



PHD

Doctorate in Clinical Psychology: Main Research Portfolio

1) The role of schemas in psychosis: a narrative review; 2) An evaluation of treatment outcomes and service users' satisfaction with Systems Training for Emotional; 3) The influence of treatment type and psychological factors on fear of recurrence, distress, and health behaviours amongst breast cancer survivors.

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Doctorate in Clinical Psychology: Main Research Portfolio

Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

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Doctorate in Clinical Psychology

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May 2015

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Critical review of the literature paper

Title of report: The role of schemas in psychosis: a narrative review.
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Abstract

Background: Schemas or core beliefs are frequently targeted in psychological approaches to psychosis. However, their precise role in the formation and maintenance of psychosis is unclear. Schema theory can shed a new light on our understanding and clinical approaches to psychosis. Therefore, this article reviews the existing research on the impact of schemas in psychosis and discusses it in relation to theory development and clinical practice.

Methods: A literature search was performed to identify studies investigating the role of schemas in psychosis. Articles were identified through a literature search in Embase, MEDLINE and Science Direct. Electronic databases were searched from inception until October 2014. A broad concept of schemas was used to identify as many relevant articles as possible. Studies investigating a concept of self-esteem were excluded.

Results: The literature search identified 753 studies of which 23 met the inclusion criteria. The reviewed studies found significant associations between negative self and other schemas and positive symptoms of psychosis in both clinical and sub-clinical samples. Negative schemas were found to be linked to trauma or adverse life events, and significantly predicted the overall variance in psychotic delusions.

Conclusions: This review highlights the importance of focusing on schemas and points to the potential role of negative self and other schemas in the development and maintenance of psychosis. The results suggest that schema theory can offer a valuable contribution to our understanding of psychosis, and has the potential to inform future research and treatment of psychosis. Limitations of the present research are discussed. Clinical and theoretical implications of findings are outlined, and possible directions for future research are suggested.

Keywords: psychosis, schemas, schema therapy, trauma, narrative review.

Key practitioner messages:

- Clinicians should be aware of the role of negative self and other schemas in the emergence of psychotic symptoms in people with psychosis, as well as those with prodromal symptoms, or those at risk of relapse.
- Clinicians should consider assessing and working with schemas during therapy, in particular with those at risk of developing psychosis or relapsing, and publishing such cases to contribute to evidence based and empirical understanding of the role of schemas in emergence of psychosis.
- Future research should focus on developing and testing treatment models for psychosis, based on its underlying psychopathology related to schemas and trauma.

Introduction

Psychosis is a severe mental health condition associated with complex comorbidity, increased risk of suicide, reduced quality of life, and poor treatment outcomes (Hawton, Sutton, Haw, Sinclar, & Deeks, 2005). Moreover, research suggests that childhood adversity and trauma is strongly associated with increased risk of psychosis (Bendall, Jackson, & Hulbert, 2010; Bendall, Jackson, Hulbert, & McGorry, 2008; Janssen et al., 2004; Read, Agar, Argyle, & Aderhold, 2003; Read, van Os, Morrison, & Ross, 2005). This is consistent with other reviews suggesting that childhood trauma and general social adversity is a risk factor not only for clinical psychiatric disorders, such as schizophrenia, but also for subclinical symptoms including psychotic-like experiences (Matheson, Shepherd, Pinchbeck, Laurens, & Carr, 2013; Varese et al., 2012; Wicks, Hjern, Gunnell, Lewis, & Dalman, 2005). Furthermore, traumatic experiences were found to be related to negative schemas (Gracie et al., 2007). Despite these findings, there is limited research investigating treatment of psychosis in the context of the wider impact of trauma or negative life events, and its interplay with schemas. This means that the needs of people with psychosis may not be met by way of specialised treatment that would focus on schemas and trauma in psychosis.

However, schema theory, proposed by Young (1990), may help to conceptualise the relationship between adverse life events, schemas and psychosis. Young et al. (2003) defined schemas as “broad, pervasive themes or patterns comprised of memories, emotions, cognitions and bodily sensations regarding oneself and one’s relationships with

others, developed during childhood or adolescence, elaborated throughout one's lifetime, and dysfunctional to a significant degree" (p.7). This definition shares similarities with Beck's (1967) early conceptualization of schemas or core beliefs.

Beck (1967) referred in his early writing to schemas, and defined them as relatively stable cognitive patterns, which provide basis for screening and information processing, and behaviours. According to Beck, individuals with a history of loss or adversity in childhood contribute to the formation of negative self or other schemas, containing dysfunctional attitudes. Dysfunctional attitudes, frequently assessed with the Dysfunctional Attitude Scale (DAS; Weissman & Beck, 1978) is often used to examine negative schemas or core beliefs, including beliefs related to success, failure, being in control, or people's approval (Beck 1967; Wang, Halvorsen, Eisemann and Waterloo, 2010). Theoretically, core beliefs and schemas are similar and represent deeper cognitive structures or patterns than automatic thoughts. Young (1990) however, has elaborated on the schema concept to emphasise the adverse relational experiences in childhood, and described schemas as the deepest level of cognitive structures.

According to Young et al., (2003) there are 18 EMS that schemas are present in every individual but are manifested in more rigid and extreme ways in people with mental health difficulties (Young et al., 2003). According to this model, schemas commonly develop during childhood in response to early trauma or adverse life events, such as abuse, neglect or criticisms (Young et al., 2003). Schemas can be grouped into five domains: (1) disconnection and rejection, (2) impaired autonomy and performance, (3) impaired limits, (4) other directedness, and (5) over vigilance and inhibition (Young et al., 2003). The full list of EMSs and schema domains are presented in Table 1.

Table 1. The Early Maladaptive Schemas (EMSs) and domains (Young et al., 2003)

| Domains | Early Maladaptive schemas |
|--|--|
| 1. Disconnection and rejection – the lack of secure attachment; feeling different and insecure | Mistrust/Abuse Abandonment/Instability Emotional Deprivation Defectiveness/Shame Social isolation/Alienation |
| 2. Impaired autonomy and performance – often overprotected or controlled as | Failure Dependence/Incompetence |

| | |
|--|---|
| children, feelings undermined and incompetent, dependent on others | Vulnerability to harm Enmeshment |
| 3. Impaired limits – limited expression of valid needs and emotions, difficulty respecting the rights of others and boundaries | Entitlement Insufficient Self control/Self discipline |
| 4. Other directedness – experienced conditional love, put the needs and wishes of others before their own | Self-sacrifice Subjugation Approval seeking/Recognition seeking |
| 5. Over vigilance and inhibition – strict parental control, frightened to express emotions | Emotional Inhibition Unrelenting standards/Hypercriticalness Negativity/Pessimism Punitiveness |

Over recent years, schema therapy (ST) has become increasingly popular with clinicians and researchers. The growing success of ST with personality disorders has raised the hope that ST may be useful for other complex, chronic mental health disorders, such as bipolar disorder or psychosis (Hawke & Provencher, 2012; Hawke, Provencher, & Arntz, 2011; Hawke, Provencher, & Parikh, 2013). It has been suggested that schema therapy could be relevant for people with severe and complex mental health difficulties, such as psychosis due to the high prevalence of early adversity and trauma and the role of environmental factors in severe mental health conditions (Birchwood, 2003; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Hawke et al., 2013). Since EMSs are considered to be the product of a difficult early environment (Young et al., 2003) and childhood adversity is high in psychosis (Bendall et al., 2010; Bendall et al., 2008; Matheson et al., 2013), schemas might play an important role in the development of psychosis. Given the complexity of psychosis and its associations with adverse life events, schema therapy has the potential to offer new insight into the development and treatment of this condition.

Existing theories of psychosis also emphasise that schemas may play a crucial role in the emergence and maintenance of psychotic symptoms. Read et al. (2005) suggested that repetitive exposure to trauma and adverse life events can have a major impact on an individual's core beliefs or schemas, and their emotional and behavioural responses to subsequent life events. These factors, combined with hypersensitivity to stress that is often

observed in people with psychosis, increase the likelihood of developing psychotic symptoms (Garety et al., 2001; Larkin, 2006; Matheson et al., 2013; Read et al., 2005).

Taken together, these conceptualisations of psychosis emphasise the potential relationship between life events, early maladaptive schemas and psychosis. After initial focus of research on self-esteem and psychosis (Kesting & Lincoln, 2013; Tiernan, Tracey, & Shannon, 2014), the field is now beginning to recognise the importance of self-concept and specific schemas in the development and maintenance of psychosis. This has led to an increased research interest in the role of schemas in psychosis, resulting in a number of new empirical and theoretical studies related to this issue. Therefore, it is now timely to systematically review studies that have investigated the associations between schemas and psychosis. This paper aims to evaluate research into the role of schemas in psychosis in order to provide an overview of the main findings in this area, and discuss it in relation to existing theories and future research development. This can contribute to a better understanding of factors involved in the emergence of psychotic symptoms, which in turn can enable us to develop more effective psychological interventions for those who suffer from this condition.

Methods

Search strategy and selection criteria

A literature search was performed to identify studies that investigated the role of schemas in psychosis. Articles were identified through a literature search in Embase, MEDLINE and Science Direct. Electronic databases were searched from inception until October 2014. The included studies investigated schemas in individuals with psychosis, those at clinical risk of developing psychosis, and the general population. The main search terms included psychosis and early maladaptive schemas or schemas as defined by Young (1990). A broad concept of schemas was used in order to identify as many relevant articles as possible. This included studies that assessed self or other schemas, core beliefs or dysfunctional attitudes. Combinations of the following keywords were used: schema*, schema therapy, core beliefs, in combination with the following disorders from the Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR (American Psychiatric Association, 2000): Psychosis, Schizophrenia, Schizoaffective disorder, Delusional disorder, Brief psychotic disorder, Substance-induced psychotic disorder, and Psychotic depression. Searches were adapted for the different databases with Boolean operators 'AND' and 'OR' to ensure the most effective searches, and were performed systematically in all databases. The reference

lists of included studies were searched in order to identify additional studies and unpublished research. Finally, researchers in the field were contacted to enquire about ongoing research or unpublished data.

Inclusion and exclusion criteria

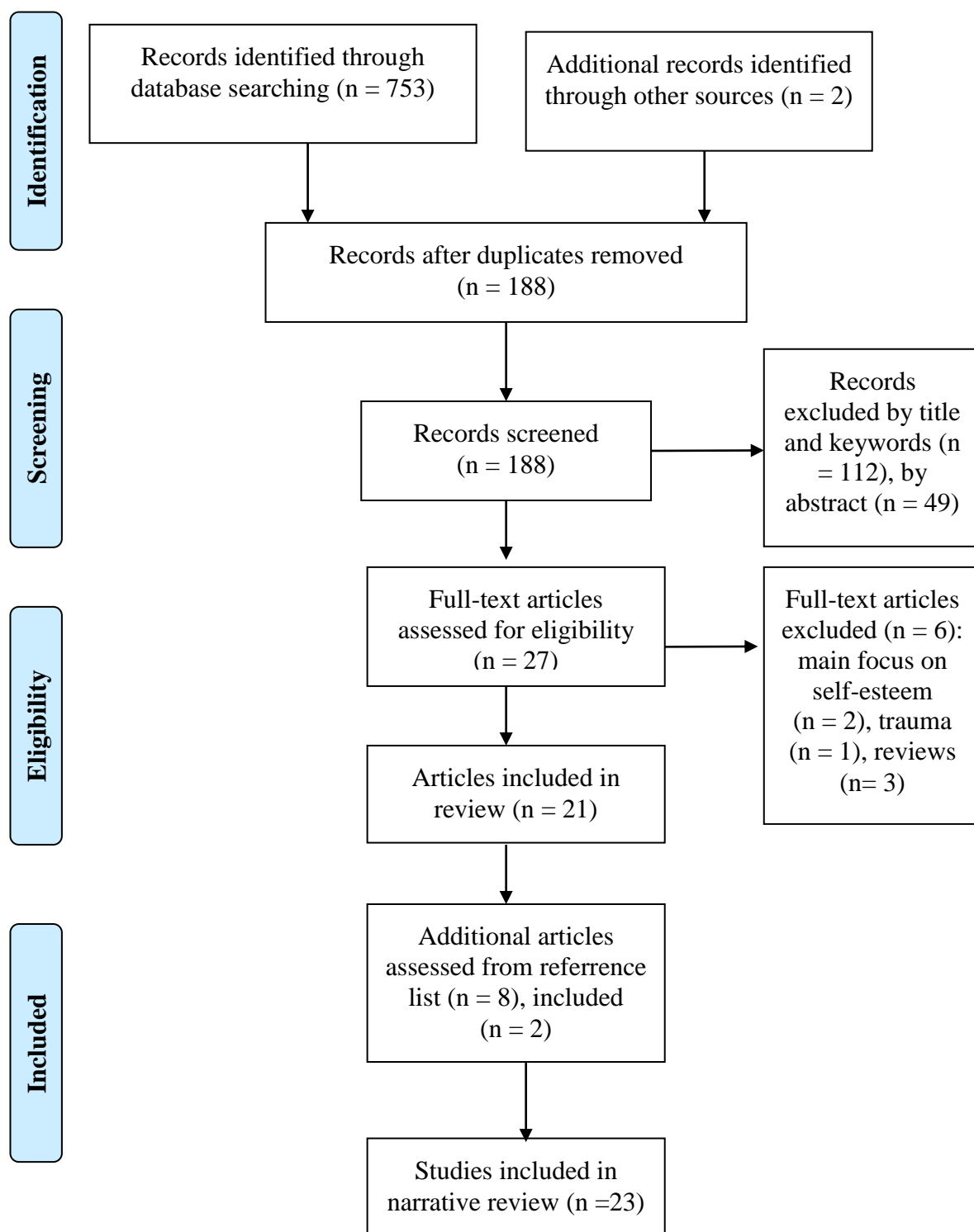
The inclusion criteria were: research articles published in English until October 2014, the study comprised of adults diagnosed with psychosis, general population and those at risk of psychosis. Because of the limited number of studies in this area, all research designs were considered including: randomized controlled trials (RCTs), controlled, uncontrolled trials, experimental, cross-sectional, prospective and longitudinal studies, as well as single case reports. Excluded from the review were studies investigating schemas in borderline personality disorder, bipolar disorder, theoretical reviews, and studies focusing on the concept of self-esteem in psychosis.

Study selection

A review of the literature was performed as recommended in the Prisma Statement (Moher et al., 2009). The electronic search yielded 753 articles. Two additional unpublished records have been identified through additional Internet searches. Following removal of duplicates 188 studies were screened for the inclusion in the review. All titles and abstracts were initially screened and irrelevant studies or purely theoretical papers were excluded. Out of 188 studies, 112 were removed on the basis of title and keywords, and 49 were excluded on the basis of abstract. Remaining 27 studies were identified for detailed screening of full-text to assess further eligibility for inclusion. Out of those, 27 articles met the inclusion criteria for the review, and 6 were excluded. Reasons for exclusion included: theoretical articles or reviews (n=3), studies focusing on self-esteem or self-concept (n=2), studies investigating trauma and psychosis (n=1). Cross-referencing of the included studies, led to identification of additional 8 studies, out of which, an additional 2 met the inclusion criteria. Thus, the total number of articles included in the review was 23.

The variables recorded included, (1) name of author and year of publication, (2) schema measure, (3) other outcome measures, (4) groups and group size, (5) main results. Quality assessment was not undertaken due to methodological differences in studies and the main focus being a narrative synthesis of the findings in this field. A flowchart of the election process is outlined in Figure 1. A narrative review was conducted as differences in the measurement and reporting of data made comparison of the main findings difficult.

Fig. 1. Flowchart outlining review process



Results

Following this selection procedure, 23 studies met all the study requirements. Table 2. provides a summary of the included studies and outlines the main outcome measures, contextual information about participants and an overview of the main findings. Due to the heterogeneity of the included studies quality scores for each study was not included.

Patient populations and group comparisons

In total, five of the studies assessed schemas in psychosis (Fowler et al., 2006; Giblin, Clare, Livingston, & Howard, 2004; Siddle, Turkington, & Dudley, 1997; Smith et al., 2006; Taylor et al., 2014), four with delusions (Bentall & Kaney, 1996; MacKinnon, Newman-Taylor, & Stopa, 2011; Moorhead & Turkington, 2001; Vorontsova, Garety, & Freeman, 2013), six explored schemas in patients with schizophrenia and other diagnosis (Bentall & Swarbrick, 2003; Bortolon, Capdevielle, Boulenger, Gely-Nargeot, & Raffard, 2013; Chung, Kim, et al., 2013; Harper, 2013; Smith et al., 2006), and two studies included individuals who hear voices (Morland, 2006; Thomas, Farhall, & Shawyer, 2013). Two studies investigated schemas in first episode of psychosis (Chung, Yoon, Park, Yang, & Oh, 2013; Taylor et al., 2014) and one in late onset of psychosis (Giblin et al., 2004).

In addition, four studies focused on non-clinical samples and investigated schemas in relation to psychotic like experiences or paranoia proneness (Fisher, Appiah-Kusi, & Grant, 2012; Fowler et al., 2006; Gracie et al., 2007; Oliver, O'Connor, Jose, McLachlan, & Peters, 2012); and four studies investigated schemas in people at high risk of developing psychosis (Addington & Tran, 2009; Saleem et al., 2014; Stowkowy & Addington, 2012; Taylor et al., 2014),

With regard to group comparisons, eight studies investigated schemas among patients with psychosis and healthy controls (Bentall & Kaney, 1996; Bentall & Swarbrick, 2003; Bortolon et al., 2013; Fowler et al., 2006; Giblin et al., 2004; MacKinnon et al., 2011; Stowkowy & Addington, 2012; Vorontsova et al., 2013), three studies used a clinical comparison group of patients with depression (Bentall & Kaney, 1996; Giblin et al., 2004; Vorontsova et al., 2013), and one examined differences in schemas in people who recovered versus those who achieved remission (Chung, Kim, et al., 2013).

Types of design and analysis

Study designs included cross-sectional, longitudinal, experimental and single case study and analyses varied from correlational and regression analyses, ANOVA and t-tests. Studies of higher quality used measures of greater validity or reliability and used larger, more representative samples, and controlled for depression and other confounding variables such as age and duration of untreated psychosis. Definition of schemas varied considerably across studies and included early maladaptive schemas as defined by Young, core beliefs, and dysfunctional attitudes. A range of outcome measures were used to assess schemas as presented in Table 1., and three studies did not include a formal measure of schemas in their design (Harper, 2013; Jakes & Rhodes, 2003; Moorhead & Turkington, 2001).

Table 2. Summary of characteristics of the 21 studies included in the review

| Study | Schema measure | Other measures | Groups and group size | Findings |
|--|--|--|--|---|
| 1. Addington and Tran (2009) | The Brief Core Schema Scales (BCSS); The Young Schema Questionnaire – short version (YSQ-S). | Scale of Prodromal Symptoms, the Calgary Depression Scale. | 1. Non-clinical at risk of psychosis (n=38) | Results suggested that the negative self and others evaluations were significantly associated with attenuated psychotic symptoms and, in particular, suspiciousness. The study found no relationship between grandiosity and positive-self in this population. |
| 2. Bentall and Kaney (1996) | The Dysfunctional Attitude Scale (DAS); Incidental recall paradigm. | The Beck Depression Inventory (BDI), The Self-Referent Incidental Recall Task (SRIRT), National Adult Reading Test (NART). | 1. Depressed deluded (n=10) 2. Non-depressed deluded (n=10) 3. Depressed controls (n=20) 4. Healthy controls (n=20) | All clinical groups, individuals with depression, persecutory delusions, and individuals with delusions with comorbid depression scored highly on the DAS. Both healthy controls, and delusional individuals (with or without comorbid depression) endorsed more positive than negative trait words as true of themselves, whereas depressed individuals endorsed as many negative as positive trait words. |
| 3. Bentall and Swarbrick (2003) | Personal Style Inventory (PSI). | The Need for Closure Scale (NCS); The Beck Depression Inventory (BDI). | 1. Schizophrenia (n=57) and delusional disorder (n=1). Out of which currently delusional (n=33) and remitted group (n=25) 2. Control group (n=57) | The study does not support the hypothesis that self-schemas play a critical role in delusional disorder. However, it suggests that both paranoid and remitted paranoid individuals are intolerant of uncertainty. |
| 4. Bortolon et al. (2013) | The Young schema questionnaire short form (YSC-S). | The Positive and Negative Syndrome Scale (PANSS); The Beck Depression Inventory-II (BDI-II). | 1. Schizophrenia (n=48) 2. Control group (n=44) | Individuals with schizophrenia scored higher than controls on six early maladaptive schemas (EMSs) after controlling for depression. EMSs were associated with positive but not negative symptoms. After controlling for depression, only Mistrust/Abuse |

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| 5. Chung, Kim, et al. (2013) | The Brief Core Schema Scales (BCSS). | The Positive and Negative Syndrome Scale (PANSS); The Scale for the Assessment of Negative Symptoms, the Personal and Social Performance Scale, the Social Functioning Questionnaire; The Schizophrenia Cognition Rating Scale (SocRS); The Basic Empathy Scale. | 1. Recovered (n=34) 2. Remitted (n=24) schizophrenia, schizophreniform disorder, schizoaffective disorder. | <p>schema was a significant predictor of positive symptoms, accounting for 12.4% of the variance.</p> <p>Positive self-schemas, cognitive and empathy scores were significantly higher in the recovered than the remitted group. There were no significant differences between recovered and remitted groups on demographic variables and duration of untreated psychosis. These results suggest positive-self schema and neurocognitive functioning may serve as important clinical characteristics distinguishing those who have recovered from those who have achieved only remission.</p> |
| 6. Chung, Yoon, et al. (2013) | The Brief Core Schema Scale (BCSS) | The Ambiguous Intention Hostility Questionnaire (AIHQ), Positive and Negative Syndrome Scale (PANSS), and Psychotic Symptoms Rating Scales. The secondary outcome measures: the Scale for the Assessment of Negative Symptoms (SANS), the Social and Occupational Functioning Assessment Scale (SOFAS), the Toronto Alexithymia Scale (TAS-20), the Trait Meta-Mood Scale (TMMS-30), the Beck Cognitive Insight Scale (BCIS), and the Scale to Assess Unawareness of Mental Disorder (SUMD). | 1. Recovered, first-episode of psychosis (n=24) | <p>The results indicated that group CBT improved the clinical status of stable outpatients with first-episode or recent-onset psychosis.</p> <p>Following the treatment scores on negative self and other schemas significantly improved even though schemas were not specifically addressed in the therapeutic sessions. Psychotic symptoms were significantly related to the BCSS scores. Although the direction of causality is not certain, this study suggested a significant relationship between negative schemas and the resolution of positive symptoms of psychosis.</p> |

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| 7. Fisher et al. (2012) | The Brief Core Schema Scales (BCSS). | The Childhood Trauma Questionnaire; The Psychosis Screening Questionnaire; The BDI; The Beck Anxiety Inventory (BAI) | 1. Non-clinical (n=212) | This study provided initial evidence for the role of anxiety and negative self-schemas in the pathway between childhood trauma and paranoia. In particular, recent anxiety and negative schemas partially accounted for the association between physical or emotional abuse during childhood and paranoia. |
| 8. Fowler et al. (2006) | The Brief Core Schema Scales (BCSS). | Rosenberg Self-Esteem Scale, Depression Anxiety Stress Scales (DASS), Paranoia Scale (PA), The Peters et al. Delusions Inventory | 1. Non-clinical (n=754) 2. Psychosis (n=252) | The negative-other evaluations were strongly and uniquely associated with paranoia in the non-clinical sample, in combination with negative-self scores and anxiety. The positive-self score strongly and uniquely predicted grandiosity in the non-clinical sample. Individuals with psychosis did not differ from non-clinical sample on self-esteem and positive evaluations of self and others, but showed very extreme negative evaluations of self and others. |
| 9. Giblin et al. (2004) | Young Schema Questionnaire—Short Version (YSQ-S). | Life experiences questionnaire. Philadelphia Geriatric Center Morale Scale-Revised. | 1. Late-onset psychosis (n=14) 2. Late-onset depression (n=13) 3. Healthy volunteers (n=18) | The late-onset psychosis group scored significantly higher than the control group on four out of five schema domains, and significantly higher than the late-onset depression group on two domains, other-directedness and over-vigilance/inhibition. Both late-onset psychosis and late-onset depression groups reported significantly higher levels of adverse life events in comparison to control group. |
| 10. Gracie et al. (2007) | The Brief Core Schemas Scale (BCSS). | The Traumatic Life Events Questionnaire; The Self-Report Scale-Post Traumatic Stress Disorder; The Paranoia Scale (PS); The Launay Slade Hallucination Scale; The Structured Interview for Assessing Perceptual Anomalies. | 1. Non clinical (n=228) | Negative beliefs about self and others were most strongly associated with a predisposition to paranoia. The study also provided support for the link between trauma and psychosis mediated by negative beliefs about self and others. |

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| 11. Harper (2013) | No formal measure of schemas. Schemas were identified through clinical questioning and Socratic dialogue. | Depression Anxiety Stress Scales (DASS), Clinical Outcomes Routine Evaluation (CORE), Qualitative outcomes (The client's reflective account of therapy). | 1. Single case study; Schizoaffective disorder (n=1) | Formulation driven therapy based on CBT, schema focused-therapy, mindfulness and compassionate mind training resulted in improvements in overall well-being and depression scores. However, anxiety, stress and functioning scores remained above the cut-off. |
| 12. Jakes and Rhodes (2003) | Evaluative beliefs scale (perceptions of self, others and what others think of self) | Degree of delusional belief (percentage conviction); Verbal scale of the degree of: (1) preoccupation with the belief; (2) distress caused by the belief; General psychosocial function: (1) Inventory of interpersonal problems (IIP); (2) Social functioning scale (SFS); (3) Hospital anxiety and depression scale (HADS); (4) Symptom questionnaire (SQ). | 1. Case series A-B-C-D design; Individuals with psychosis and delusions (n=5). | The treatment components were administered sequentially and included (1) Solution-focused Therapy (2) Schema-focused cognitive therapy (3) Cognitive therapy focused on modification of the delusion. Two clients showed reduction in degree of belief in their delusion during solution-focused therapy, one client improved during cognitive challenging of the delusion and one client changed during baseline. Negative beliefs about the self and other improved in all clients. |
| 13. MacKinnon et al. (2011) | The Brief Core Schema Scales (BCSS). | The Implicit Association Test (IAT); Rosenberg Self-Esteem Scale; The Social Interaction Anxiety Scale (SIAS); The Depression Anxiety Stress Scale-21 (DASS-21). | 1. Persecutory delusions (n=16) 2. Healthy controls (n=20) | Individuals with persecutory delusions reported significantly higher negative self and other schemas as compared to healthy control group. However, they showed positive implicit self-esteem, as compared to control group. Explicit self-esteem was lower in the persecutory delusion group, and was related to higher levels of depression and anxiety in clinical sample. |
| 14. Moorhead and Turkington (2001) | The Schema Questionnaire (SQ); Young's Parenting Inventory (YPI). | The Maudsley Assessment of Delusions Scale (MADS); The Comprehensive Psychopathological Rating Scale (CPRS) | 1. Single case study (n=1) delusional disorder | The study found similarity among the schemas, the triggering event, and the psychotic content. Beliefs that mediate the relationship between main schemas and delusional beliefs may form a helpful focus for early therapeutic work in psychosis. |

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| 15. Morland (2006) | Young's Schema Questionnaire (SQ). | The Revised Edition of the Belief About Voices Questionnaire. | 1. Range of diagnosis; all hearing voices (n=51) | The study indicated significant relationship between early maladaptive schemas (EMSs) and the belief people hold about their voices. Malevolence and Omnipotence were positively associated with several EMSs and Benevolence showed negative correlations. This suggested that beliefs about voices may reflect the wider beliefs people hold about themselves and social context. |
| 16. Oliver et al. (2012) | Brief Core Schema Scale (BCSS). | Delusional Ideation: The Peters et al. Delusion Inventory (PDI); Negative Schemas: Depression, Anxiety and Stress Scale (DASS), Psychological flexibility: Acceptance and Action Questionnaire II (AAQ). | 1. Non-clinical sample (n=700) at Time 1 2. Non-clinical (n=204) at Time 2 (6 months later) | Negative schemas significantly predicted higher rates of delusional thinking in non-clinical sample. The relationship between negative schemas and delusional thinking was partially mediated through anxiety. This indirect effect was moderated by psychological flexibility. Negative schemas significantly predicted higher rates of delusional thinking 6 months later, and this effect was fully mediated through anxiety. |
| 17. Saleem et al. (2014) | The Brief Core Schema Scale (BCSS) | The Structured Interview for Prodromal Syndromes (SIPS) and the Scale for Assessment of Prodromal Symptoms (SOPS), Perceived Discrimination measure. | 1. Clinical high risk of psychosis (n=360) 2. Non-clinical (n=180) | People at clinical high risk for developing psychosis endorsed a higher level of perceived discrimination, which is associated with increased negative schemas but not attenuated positive symptoms. |
| 18. Siddle et al. (1997) | The Dysfunctional Attitude Scale (DAS). | The Comprehensive Psychopathological Rating Scale (CPRS). | 1. Single case study (n=1) psychosis | The study describes formulation driven treatment of psychosis, based on schema-focused interventions. The results indicated significant improvement is overall psychopathology symptoms, including a substantial reduction in schizophrenia and depression subscales, and improvements in social functioning. |
| 19. Smith et al. (2006) | The Brief Core Schema Scales (BCSS). | Scale for the Assessment of Positive Symptoms (SAPS); Positive and Negative Syndrome Scale (PANSS); | 1. Non-affective psychosis (schizophrenia, schizoaffective disorders, delusional disorder) with | Higher depression, lower self-esteem and more negative self and others schemas were related to higher severity of persecutory delusions and more pre-occupation and distress caused by them. Grandiose |

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| | | Psychotic Symptom Rating Scales; Beck Depression Inventory-II; Rosenberg Self-esteem Scale (RSES). | a recent relapse (n=100) | delusions were positively associated with higher self-esteem, lower depression, less negative self-evaluations. |
| 20. Stowkowy and Addington (2012) | The Brief Core Schema Scale (BCSS). | The Structured Interview for Prodromal Symptoms (SIPS) and the Scale for Assessment of Prodromal Symptoms (SOPS); The Calgary Depression Scale; The Social Defeat Scale. | 1. Non-clinical at high risk for psychosis (n=38) 2. Healthy controls (n=23) | The results showed higher levels of social defeat and negative self and others schemas in people at risk of psychosis. Negative schemas mediated the relationship between social defeat and early symptoms of psychosis. This study provides preliminary support for the notion that maladaptive schemas play a role in the onset of psychosis. |
| 21. Taylor et al. (2014) | Brief Core Schema Scales (BCSS). | The Comprehensive Assessment for At Risk Mental States (CAARMS). | 1. First episode of psychosis (n=20) 2. At risk mental state (n=113) 3. Help-seeking clinical group with no history of psychosis (n=28) 4. Non-help seeking individuals with some psychotic like experiences (n=30). | The clinical groups scored significantly higher than the non-help seeking group on both negative beliefs about self and others. There were no significant differences between groups on positive other schemas. The non-help seeking group showed significantly higher scores on positive self-schemas than the clinical groups. Negative self and others schematic beliefs were associated with positive symptoms of psychosis and distress associated with those symptoms. |
| 22. Thomas et al. (2013) | Brief Core Schema Scales (BCSS). | Psychotic Symptom Rating Scales Auditory Hallucinations Subscale (PSYRATS); Interpretation of Voices Inventory (IVI); Revised Beliefs About Voices Questionnaire (BAVQ-R; The Positive and Negative Syndrome Scales (PANSS). | 1. Schizophrenia or schizoaffective disorder – hearing voices (n=34) | Negative schemas were significantly related to negative beliefs about voices and negative voice content among people hearing voices. After controlling for negative voice content, schemas predicted between 9% and 35% of variance in the six beliefs about voices that were measured. Negative-self schemas were the strongest predictors of beliefs about voices. |

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| 23. Vorontsova et al. (2013) | The Brief Core Schemas Scale (BCSS) | The Schedules for Clinical Assessment in Neuropsychiatry (SCAN); The Psychotic SYmptom RATing Scales: Delusions scale (PSYRATS); The Green et al. Paranoid Thoughts Scale (GPTS); Beck Depression Inventory (BDI); Beck Anxiety Inventory (BAI), The Avoidance and Action Questionnaire (AAQ); The Ruminative Response Scale (RRS); The Penn State Worry Questionnaire (PSWQ); Autobiographical Memory Test (AMT); Means-Ends Problem-Solving; The Wechsler Test of Adult Reading (WTAR); Verbal fluency test. | 1. Persecutory delusions (n=60) 2. Depression (n=30) 3. Healthy controls (n=30) | Cognitive processes associated with depression across the groups were negative schematic beliefs about the self, experiential avoidance and rumination. The severity of initial depression, negative self-schemas, worry and problem solving difficulties predicted the persistence of paranoia over six months amongst individuals with delusions. |
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Summary of the main results regarding schemas and psychosis

Research evidence from the reviewed studies suggest that negative self and other-schemas are associated with positive symptomatology in both clinical (Bortolon et al., 2013; Fowler et al., 2006; Giblin et al., 2004; MacKinnon et al., 2011; Smith et al., 2006; Taylor et al., 2014; Thomas et al., 2013; Vorontsova et al., 2013) and non-clinical populations (Addington & Tran, 2009; Fisher et al., 2012; Gracie et al., 2007; Oliver et al., 2012; Stowkowy & Addington, 2012). For instance, Bortolon and colleagues (2013) found that early maladaptive schemas predict positive symptoms in a sample of individuals with schizophrenia. However, after controlling for depression the Mistrust/Abuse schema was the only significant predictor of positive symptoms and accounted for over 12% of the total variance (Bortolon et al., 2013). Similarly, other studies found that negative schemas were related to positive symptoms of psychosis and distress associated with those symptoms (Taylor et al., 2014). With regard to paranoia, the results of this review indicated that negative other schemas predicted the severity of paranoia or paranoia proneness both in the clinical sample and in the general population (Fisher et al., 2012). However, Bentall and Swarbrick (2003) findings did not support the notion that self-schemas play a critical role in the formation of delusions. Instead, they emphasised high levels of intolerance of uncertainty, high subjective need for order, and difficulty coping with uncertainty in currently paranoid and remitted paranoid individuals (Bentall & Swarbrick, 2003).

Between group discrepancies - comparisons with depressed patients

Group comparisons revealed that patients with delusions reported more positive self-schemas as compared to patients with depression, and those who are depressed and deluded (Bentall & Kaney, 1996; Vorontsova et al., 2013). However, patients with delusions regardless of whether they were depressed or not, had more dysfunctional self-schemas compared to healthy controls (Bentall & Kaney, 1996). Vorontsova et al. (2013) study indicated that depression occurs in up to 50% of people with persecutory delusions and the severity of initial depression, negative self-schemas, worry and deficits in problem solving, predicted the persistence of paranoia over six months (Vorontsova et al., 2013).

Another study that compared people with late-onset depression to people with late-onset psychosis indicated that people with psychosis scored higher on two schema domains including other-directedness and over-vigilance/inhibition (Giblin et al., 2004). This provides preliminary evidence that schemas may be particularly salient for late-onset psychosis as opposed to late-onset depression (Giblin et al., 2004).

Taken together, these results suggest that patients with psychosis report significantly more positive self-schemas as compared to patients with depression. This is consistent with previous research indicating that global self-esteem is enhanced in persons with delusions, when compared to patients with depression (Kesting & Lincoln, 2013). However, it needs noting that the validity of the Giblin et al. (2004) study is limited since they used Young Schema questionnaire that has not been validated in older populations. Bentall and Kaney (1996) study employed indirect measures of schematic processes, such as Dysfunctional Attitudes Scale and incidental recall of adjectives that are not designed to assess specific self and other schemas. Given those limitations, the finding that patients with persecutory delusions and psychosis show more positive self-schemas than patients with depression can be considered preliminary.

Schemas in people at risk of psychosis

Eight studies investigated schemas in people at clinical risk of developing psychosis or sub-clinical levels of psychosis (Addington & Tran, 2009; Fisher et al., 2012; Fowler et al., 2006; Gracie et al., 2007; Oliver et al., 2012; Saleem et al., 2014; Stowkowy & Addington, 2012; Taylor et al., 2014). Research findings in this area consistently indicated that negative self and other schemas are significantly associated with attenuated symptoms of psychosis (Addington & Tran, 2009). For instance, Fowler and colleagues (2006) found that negative-self and other schemas as well as anxiety were strongly and uniquely associated with paranoia in non-clinical samples. This is consistent with another study indicating that negative schemas, in particular negative other schemas, uniquely predicted prodromal symptoms of psychosis, such as suspiciousness (Addington & Tran, 2009). Interestingly, Oliver et al. (2013) described the processes by which negative schemas promote delusional thinking in healthy individuals. They found that the negative schemas predicted higher rates of delusions, and the relationship between negative schemas and delusions was partially mediated through anxiety (Oliver et al., 2012). This effect was moderated by psychological flexibility (Oliver et al., 2012). Finally, it is important to note that the results regarding positive self-evaluations and grandiosity were mixed. While some studies found that the positive-self schemas were significant predictors of grandiosity and were related to higher self-esteem (Fowler et al., 2006; Smith et al., 2006), others found no significant association between grandiosity and positive self-schemas in people at risk of psychosis (Addington & Tran, 2009).

Associations between trauma, schemas and psychosis

Four studies investigated trauma and adverse life events, and their impact on the development of schemas and psychotic symptoms (Fisher et al., 2012; Giblin et al., 2004; Gracie et al., 2007; Stowkowy & Addington, 2012). For instance, Fisher et al. (2006) found initial evidence for the role of anxiety and negative self-schemas in the pathway between childhood maltreatment and paranoia. This finding was corroborated by Gracie et al. (2007) research indicating that negative schemas, and PTSD symptoms related to adverse life events were significantly associated with a predisposition to hallucinations and paranoia in the general population. The same study found that negative self and other schemas contributed to 29% and 32% of the variance in paranoia respectively (Gracie et al., 2007). Those results are in accord with the findings of the previous studies conducted with clinical samples (Giblin et al., 2004). Thus, research in this area seems to offer preliminary but consistent support for the hypothesis that maladaptive schemas can mediate the relationship between trauma and psychosis (Gracie et al., 2007; Stowkowy & Addington, 2013).

Hearing voices and adverse life events

In addition, some research studies included indicated that core schemas might also play a role in formation of beliefs about voices (Morland, 2006; Thomas et al., 2013). This is partially consistent with the finding that beliefs about voices were correlated with both negative voice content and schemas, and negative self-schemas were the strongest predictors of beliefs about voices (Thomas et al., 2013). Research also suggested that schemas may influence the appraisal of voice in terms of power and also voice intent (e.g. malevolence) (Thomas et al., 2013). Thus, it appears that negative beliefs, in particular negative-self schemas, are potentially important in the formation of a range of beliefs, or interpretation of voices.

The role of schemas in relapse, remission and recovery from psychosis

Research comparing the characteristics of people who remitted and those who recovered from schizophrenia indicated that positive self-schemas, higher empathy scores and better neurocognitive functioning were significantly higher in the recovered group than the remitted (Chung, Kim, et al., 2013). This is significant given that the participant in those two groups did not differ significantly on demographic variables or duration of untreated psychosis (Chung, Kim, et al., 2013). Studies of individuals who recently relapsed show that more negative self and other schemas were related to higher levels of paranoid delusions, as well as being more pre-occupied and distressed by them (Smith et al., 2006).

Findings from case studies and group CBT for psychosis research

Finally, three case studies and one case series described the use of different aspects of schema-focused work in the treatment of psychosis (Harper, 2013; Jakes & Rhodes, 2003; Moorhead & Turkington, 2001; Siddle et al., 1997), and one study reported findings from the CBT treatment for psychosis (Chung, Yoon, et al., 2013). Overall, the results were promising and indicated benefits to using schema work as a treatment of psychosis, with one study indicating improvements in negative self and other schemas following group treatment for psychosis (Chung, Yoon, et al., 2013). Additional outcomes reported in previous case studies include improvements in psychological distress and functioning and overall better quality of life (Harper, 2013; Moorhead & Turkington, 2001; Siddle et al., 1997). The results of one study that used a series of single case experiments comparing a stable baseline with an active treatment found that solution-focused therapy was more effective at reducing degree of conviction in psychotic delusions, than schema focused work (Jakes & Rhodes, 2003). This is however, not surprising given that schema therapy in this study did not specifically target delusional conviction. Moreover, as the order of treatment was confounded in this study it is not possible to say if the solution focused therapy was more effective because it was the first treatment or because of its particular characteristic (Jakes & Rhodes, 2003). However, it is important to note that the validity of those results is limited due to methodological weaknesses of those studies and lack of formal assessment of schemas and schema change in three of the included case studies (Harper, 2013; Jakes & Rhodes, 2003; Moorhead & Turkington, 2001).

Discussion

Overall, this review indicates the importance of schemas in the development and maintenance of psychosis. The main findings from the included studies suggest a significant relationship between negative schemas and positive symptoms of psychosis. In particular, research demonstrated the significance of negative self and other schemas in the formation of positive symptoms amongst clinical and sub-clinical samples (Addington & Tran, 2009; Fowler et al., 2006; MacKinnon et al., 2011; Smith et al., 2006). Furthermore, some studies suggested that negative self-schemas were independently associated with delusions, even when the confounding effects of low self-esteem and depression were controlled for (Smith et al., 2006). Negative self-schemas were also found to be associated with distress related to hallucinations, and the intensity of its negative content (Smith et al., 2006). Thus, these results seems to indicate that people with psychosis show extreme self

and other schemas that are related to positive symptoms of psychosis, and this effect is independent of the impact of mood.

Interestingly, the reviewed studies indicated that people with psychosis did not differ significantly from healthy individuals, on measures of positive self-schemas, and reported more positive self-schemas than individuals with depression (Fowler et al., 2006; MacKinnon et al., 2011; Smith et al., 2006). Thus, it seems that positive self-schemas are maintained, or at least less impaired in individuals with psychosis (Fowler et al., 2006; Kesting & Lincoln, 2013; Smith et al., 2006). This is in contrast to non-clinical samples, which tend to report more positive and fewer negative self-evaluations, and to people with depression, who report more negative and fewer positive self-evaluations (Kesting & Lincoln, 2013; Tiernan et al., 2014). These findings are consistent with previous reviews investigating the relevance of self-esteem or self-concept in psychosis (Kesting & Lincoln, 2013; Tiernan et al., 2014).

Therefore, the notion that negative schemas are relevant in psychosis, as proposed by the existing theories, has preliminary support in empirical research. However, the mechanisms behind those associations remain unclear. The results of Smith et al. (2006) study suggest that there may be different association for different symptoms. For instance, they found that negative self-schemas were independently associated with persecutory delusions but not with auditory hallucinations (Smith et al., 2006).

Schemas in people at high risk of psychosis and those who recovered

Secondly, the reviewed studies indicate that schemas may be particularly relevant in prodromal psychosis. The reviewed studies in this domain consistently indicate that negative self and other schemas predicted higher levels of paranoid ideation in non-clinical samples, while elevated positive self-schemas predicted grandiosity (Fowler et al., 2006; Smith et al., 2006). Furthermore, Chung et al. (2013) showed that positive self-schemas might be important clinical characteristic distinguishing those who recovered compared to those who achieved remission (Chung, Kim, et al., 2013; Smith et al., 2006). However, the validity of these findings are restricted by the use of non-clinical samples and cross-sectional design. Therefore, further research his warranted to corroborate these findings and evaluate its generalizability to clinical samples.

Trauma and psychosis

Finally, there is preliminary evidence indicating the role of negative self-schemas in the pathway between childhood trauma and psychosis (Fisher et al., 2012). This proposal is corroborated by evidence that negative schemas were significantly associated with predisposition to paranoia (Giblin et al., 2004; Gracie et al., 2007). However, it is noteworthy that these results are based mostly on retrospective, cross-sectional research with non-clinical samples. Therefore, further research is warranted to establish the validity and generalizability of these findings. Nevertheless, these results are of interest, and are consistent with the current theories indicating the potential role of schemas in the development and maintenance of psychotic symptoms (Birchwood, 2003; Garety et al., 2001).

Theoretical overview and conceptualization of the potential role of schemas in psychosis

In order to provide an explanation of how schemas can impact and interact with positive symptoms of psychosis, it is important to integrate current models of psychosis with the research evidence in this area. Firstly, it is important to note that previous research points to a significant link between adverse life events and interpersonal stressors, and an increased risk of developing psychosis (Matheson et al., 2013; Read et al., 2005) and early maladaptive schemas (Young, 1990). This is of particular interest since negative self and other evaluations have been incorporated into different models of paranoia and persecutory delusions (Bentall, Corcoran, Howard, Blackwood, & Kinderman, 2001; Bentall & Swarbrick, 2003; Birchwood, 2003; Garety et al., 2001). More specifically, Garety et al. (2001) proposed that early traumatic experiences could contribute to the formation of negative schemas, which in turn can have an impact on delusional beliefs and emotional distress. These theories are consistent with evidence for the role of negative schemas, anxiety (Fisher et al., 2012) and depression (Garety et al., 2001) in the pathway between childhood maltreatment and psychosis. They are also consistent with research indicating that schematic beliefs mediate the relationship between lifetime trauma and paranoia in the general population (Gracie et al., 2007).

In line with these findings, it is therefore possible that early maladaptive schemas become reactivated in response to stress and difficulties with social relationships in a vulnerable person (Bortolon et al., 2013; Fisher et al., 2012). These reactivated schemas can then lead to increased levels of stress and anxiety which can have a negative effect on information processing and cognitive biases, including jumping to conclusions (Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002). These responses can be exacerbated by the deficits

in emotion regulation and vulnerability to stress (Freeman et al., 2002; Garety et al., 2001; Read et al., 2005). Taken together, all those factors can contribute to increased anxiety and paranoid misinterpretations of ambiguous situations, in a vulnerable person predisposed to developing psychosis (Freeman et al., 2002; Garety et al., 2001). Psychotic symptoms could therefore be explained to emerge as a function of reactivated schemas, in the context of previous trauma or adverse life events, deficits in effective emotion regulation, and maladaptive cognitive and emotional responses to stress (Birchwood, 2003; Freeman et al., 2002; Garety et al., 2001; Morrison, Frame, & Larkin, 2003). The experience of psychosis can then lead to social withdrawal, shame and stigma, which in turn can increase distress, and confirm negative self and other beliefs thus maintaining the vicious cycle.

Existing theories of psychosis, considered in this paper, explain the relationship between adverse life events and schemas, and provide us with a valuable knowledge upon which to base further research into the role of schemas in psychosis. However, future research in this area should move away from correlational design, towards more experimental, longitudinal, and treatment studies, to test those theories, and provide new implications for clinical practice. Linked to this, it is striking that this review revealed a significant number of articles investigating the relationship between schemas, trauma and psychosis, but a comparatively small number of treatment studies that would address schemas in people with psychosis. Furthermore, research and theories seem to indicate that previous trauma or adverse life events are likely to be prominent features in many people struggling with psychosis. However, the sparse treatment studies discussed in this review did not tailor their treatment to directly explore schemas and trauma, which may contribute to the development and maintenance of psychosis. Instead, schemas in the context of previous trauma and psychosis seem to be almost ignored in the treatment literature to date.

Limitations

It is important to note some limitations of the present review. The majority of the studies included in this review have used cross-sectional design to investigate the role of schemas in psychosis. This precludes conclusions regarding causality, and does not clarify whether negative schemas are the cause or the consequence of psychosis (Smith et al., 2006). Therefore, as already mentioned more experimental or longitudinal research is warranted to further investigate the stability or change of schemas over time, and its impact on psychosis. The generalizability of the present findings is limited by the use of highly heterogeneous, self-selecting and non-clinical samples that may not be fully representative of people with psychosis.

Additional methodological limitation in this field of research relates to the use of different definitions and measurement of schemas (i.e. schemas, core beliefs, dysfunctional attitudes). It would therefore be of value for future research to investigate the conceptual overlap between EMS, core beliefs and dysfunctional attitudes in order to establish whether these separate definitions are indeed necessary and appropriate. Future research trials would benefit from the use of clear, and consistent operational definition of schemas, and its measurement. A further limitation of the present study is that it included only studies published in English and may be confounded by the publication bias.

Clinical and research implications

The findings of the present review have a number of implications for theory, clinical practice and future research. First of all, further research is needed to prove the utility of schema theory in improving our understanding of the development, maintenance and treatment of psychosis. Inclusion of a control clinical group would be a valuable addition to the field, in order to evaluate patterns of schemas across different clinical groups. Furthermore, future studies in this area should aim to include larger sample sizes and greater consistency in methodology. In particular, a clear operational definition of schemas, and use of validated schema measures, such as The Brief Core Schema Scale (Fowler et al., 2006) would be beneficial, as mentioned above. This would improve the quality of research and facilitate comparison of findings across different studies. Future research would also benefit from longitudinal research to evaluate the stability or change of schemas across time, and its impact on psychotic symptoms. Finally, it could be interesting for future studies to explore whether fluctuations in negative and positive schemas could be used as a clinical indicator of early signs of relapse.

In terms of clinical applications, the present study indicates that schema theory may offer a promising way of conceptualising the development of psychosis. Greater understanding of the pathways between schemas and psychosis, and the role of trauma in this process, could contribute to the development of preventative or therapeutic interventions for people with psychosis, or those at clinical high risk for psychosis (Fisher et al., 2012; Smith et al., 2006). Although schema therapy in its original form has not been indicated for individuals with active psychosis (Young, 2003), clinicians could adapt their formulations and apply schema-based interventions to their work. This is particularly important in the light of the scarcity of treatment literature in this area. More research could bring new insight into treatment of psychosis, and allow comparison of the effectiveness of schema-focused therapy with other evidence-based treatment for psychosis.

Conclusions

This study presents the results of a literature search pertaining to the role of schemas in psychosis, and provides preliminary support for the notion that schemas play an important role in the emergence and maintenance of psychotic symptoms. An improved understanding of the specific mechanism involved in the development of schemas and psychosis could lead to better prevention or management of this condition. This provides a rationale to continue expanding research in this area, and develop new therapeutic interventions to support people who suffer from psychosis.

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Service Improvement Project

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Abstract

This paper reports on an evaluation of a pilot implementation of a Systems Training for Emotional Predictability and Problem Solving (STEPPS) programme delivered within a secondary care service in the UK. The paper will present a brief review of the relevant literature regarding the development and evaluation of the STEPPS programme, followed by the results of a pilot study of the effectiveness of the STEPPS intervention and client's satisfaction with services within the UK secondary care setting. Although the participants found the programme acceptable, there was little evidence for its effectiveness. Recommendations for clinical practice and further research are presented.

Introduction

Borderline personality disorder (BPD) is characterised by significant instability of interpersonal relationships, self-image and mood, fear of abandonment and rejection (Levy et al., 2006). This is often accompanied by a strong tendency towards impulsive behaviour, suicidal thinking and self-harm (APA, 1994). Research suggests that BPD occurs in approximately 1–4% of the general population, 10–15% of psychiatric outpatient population, and up to 20% of psychiatric inpatients (Lenzenweger, Loranger, Korfine, & Neff, 1997; Torgersen, Kringlen, & Cramer, 2001; Widiger & Weissman, 1991; Zimmerman, Rothschild, & Chelminski, 2005). There is also evidence that BPD is often associated with poorer quality of life, co-morbid mental health conditions such as depression and anxiety, and excessive use of the health care system (Blum et al., 2002).

The National Institute for Health and Clinical Excellence (NICE) currently recommends several evidence-based treatments for the management of BPD (NICE, 2009). These include Dialectical-Behaviour Therapy (Linehan, 1993; Linehan, Armstrong, Suarez, Allmon, & Heard, 1991; Linehan et al., 2006), Cognitive-Behavioural Therapy (CBT) (Davidson et al., 2006), Schema-Focused Therapy (Giesen-Bloo et al., 2006), and Mentalization-Based Therapy (Bateman & Fonagy, 2010). Despite an increasing body of research evaluating the outcomes of these psychological treatment approaches, NICE suggested that the evidence for these treatment models is not conclusive (NICE, 2009). Unfortunately, all of these approaches are costly and involve long-term treatment plans. Hence, recent efforts have focused on developing a model of treatment for BPD that is cost-effective and efficient in reducing psychological distress, self-harm as well as

inpatient admissions associated with BPD. One of the most promising of these is the Systems Training for Emotional Predictability and Problem Solving programme (STEPPS) (Blum, Pfohl, St John, Monahan, & Black, 2002).

STEPPS is a programme that employs aspects of CBT, alongside a systemic component, recognising the importance of support from a person's family and friends. It was adapted from a twelve-week psycho-educational programme developed by Bartels and Crotty (1992). It was then extended to a twenty-week programme with specific facilitator guidelines and agendas for each week of the treatment (Black, Blum, & St. John, 2009; Blum et al., 2009). The STEPPS treatment is divided into two distinct but overlapping parts, with the first twelve sessions focusing predominantly on psycho-education about BPD, emotional management skills and development of adaptive coping strategies. The remaining eight sessions focus on behaviour management skills, including goal-setting, interpersonal relationship management, abuse, avoidance, sleep hygiene and nutrition, exercise and physical health (Black, Blum, & St. John, 2009). There is a growing evidence base for the effectiveness of the STEPPS programme, with a number of uncontrolled trials reporting significant improvements in mood and functioning, and reductions in the degree of impairment associated with BPD (Black et al., 2009; Blum et al., 2002; Stoffers et al., 2012). Perhaps most importantly, a Randomized Controlled Trial (RCT) comparing STEPPS plus treatment as usual, to treatment as usual alone found that STEPPS led to significant improvements in functioning, depression and BPD related symptoms and behaviours (Blum & Black, 2008). In particular, it has been shown that the STEPPS programme has been associated with a reduction in impulsive behaviours, self-harm, and symptoms of depression and anxiety (Blum et al., 2008; Black et al., 2009). Blum et al., (2002) stated that in their experience, most patients will have benefited from STEPPS, and will report improvement in their symptoms, and control over impulsivity and self-harm behaviours (Blum et al., 2002). However, many may need a longer follow-up in order to internalize the lessons and practice their skills (Blum et al., 2002). Therefore, Blum et al., (2002) recommended a one-year, twice monthly extension programme called STAIRWAYS (an acronym for Setting goals; Trusting and taking risks, Anger management, Impulsivity control, Relationship behaviour, Writing a script, Assertiveness training, Your journey, and Schemas revisited). The main focus of STAIRWAYS is to maintain the skills learned in STEPPS, whilst providing a lower intensity of service (Blum et al., 2002).

According to the World Health Organisation (WHO, 2000), attempts to evaluate client's satisfaction is an excellent opportunity to involve patients in the process of evaluating

services (WHO, 2000). Pisarski (2011) and colleagues suggested that careful consideration of client's satisfaction with services could enhance the process of redesign of services and lead to more effective and acceptable care. This suggests that investigation of client's views and perceptions of their treatment should be a crucial aspect of service evaluation. Other research suggests that clients' perceptions of their treatment can have a major impact on their adherence, and subsequent treatment outcomes (Ruggeri, 1994). This is of particular importance for individuals with BPD who are at higher risk of premature discontinuation of treatment (Black et al., 2009). Therefore, evaluation of client's satisfaction could potentially help to identify factors associated with an increased risk of drop out from services. This in turn could enable service providers to address those issues more effectively, although it is important to note that research on the relationship between client's satisfaction and outcomes in mental health services have been limited and somehow inconsistent (Turchik et al., 2010; Garland, Haine and Boxmeyer, 2007; Hasler et al., 2004).

There is yet to be an evaluation of clients' satisfaction with the STEPPS programme delivered within the UK secondary care services. This brings us into the aims and scoping of this project.

Scoping of the project

Consultation with the Psychological Therapies Service (PTS) in South West England revealed that the support offered to clients referred with BPD features was not sufficient in meeting the needs of this group. Consequently, the service providers proposed setting up a pilot STEPPS group that would constitute an additional treatment choice for people with BPD. Subsequent consultation within the team focused on establishing the most appropriate set up of the group, and outcomes measures that would be used to evaluate outcomes of this programme. In collaboration with the service, it was agreed that data from the STEPPS programme would be used to offer recommendations for service improvement, with the aims of improving therapy offered to people with BPD.

The main aims of this study were to evaluate: (1) the outcomes of a pilot Systems Training for Emotional Predictability and Problem Solving (STEPPS), and (2) based on the previous literature to evaluate client's satisfaction with their treatment and overall service provision, in order to identify potential areas for service improvement.

Method

Design

The present evaluation used a mixed method design. More specifically, it employed a combination of quantitative methodology (i.e. evaluation of the pre and post-treatment outcomes), alongside the evaluation of qualitative feedback from participants regarding satisfaction with their treatment and service concerned.

Approach

Analyses were performed using SPSS 22 (SPSS Inc. IBM, Chicago, Illinois, USA), with statistical significance set at $p < 0.05$. In addition, thematic analysis was applied as a method of analyzing qualitative data from surveys. This approach allowed for identification of emergent themes not explicitly stated in survey questions (Braun & Clarke, 2006). It also enabled more in-depth analysis of participants' personal experiences of the STEPPS programme and their satisfaction with the overall service. According to Braun and Clarke (2006), a thematic analysis involves a series of phases that allow for exploration of personal meaning for participants, whilst maintaining the flexibility associated with this epistemological position. The theoretical framework is based on organizing key issues emerging from data, and grouping them into themes reflecting important aspects of personal experiences attached to a particular subject in question (Braun & Clarke, 2006).

Participants

Fourteen people were referred to the psychological therapy service to take part in the STEPPS programme, by their respective community mental health team care coordinators. Subsequently, twelve participants were invited to a pre-group assessment session, and of those nine attended the STEPPS programme (N=9). The reasons for not choosing STEPPS, included a preference to undertake an alternative therapy namely Dialectical Behaviour Therapy (DBT) (N=1), time commitments (N=1), anxiety about attending group (N=1), and other reasons not specified (N=2). All participants were females, and had the mean age of 34, (range 19 to 70); eight participants were white British, one was mixed-race.

Measures

The following measures were used to evaluate the STEPPS group and service user's satisfaction with the service provision:

The Borderline Evaluation of Severity Over Time (BEST) is a self-report questionnaire designed by Pfohl et al. (2009) to assess the degree of impairment or interference from each of the nine BPD criteria over the past week (Pfohl et al., 2009). It is rated on a five-point scale, with scores ranging from 12 to 72, with the higher scores indicating higher levels of severity. The BEST scale has moderate test-retest reliability, high internal consistency, and high discriminate validity (Pfohl et al., 2009).

The Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) is a self-report measure that is widely used to assess outcomes from psychological therapy (Barkham et al, 2001; Evans et al, 2002). The CORE-OM comprises 34 items addressing domains of subjective well-being, symptoms, functioning, and risk. Items are scored on a five-point scale ranging from 0 ('not at all') to 4 ('all the time'). The total score can range from 0 to 140, with a cut-off point of 20 for healthy sample, 21-33 low levels of distress, 34-50 mild, 51-67 moderate, 68-84 moderate to severe, 85+ severe.

The Service User Satisfaction Survey was used to evaluate different aspects of client's satisfaction with service delivery (Pisarski et al., 2011). The survey includes five sections measuring the (1) overall satisfaction, (2) satisfaction with information and contact with the clinic, (3) waiting times, (4) questionnaires, and (5) the treatment. A blank space was available at the end of each section to allow suggestions regarding how that specific area could be improved. A longer blank space was available at the end of the questionnaire for any further comments (Pisarski et al., 2011). The responses are rated on a five-point Likert scale, with one question being reverse scored. The scores can range from 0 to 75, with the higher scores indicating higher levels of satisfaction with the specific area (Pisarski et al., 2011).

The STEPPS Evaluation Survey was adapted by the researcher and the service from a questionnaire described in Blum et al. (2002). The specific adaptation included a change of the rating scale from a seven-point Likert scale to a five-point Likert scale, to make the survey more accessible, and exclusion of one question that was considered less relevant for the purpose of this evaluation (i.e. "My therapist did not agree with what I was taught"). Those changes were deemed acceptable, as the survey has no reported established reliability, therefore changing the structure of it would not affect its reliability. The final scale included 13 items, with one question being reverse coded. The total score can range from 0 to 65, with higher scores indicating higher level of satisfaction with treatment.

Procedure

Two facilitators ran the group and collected outcome measures. The main facilitator was a Chartered Clinical Psychologist, experienced in running groups. The co-facilitator was a Trainee Clinical Psychologist, which changed towards the end of sessions to another clinician. The outcome measures were collected as a routine part of the service evaluation. The BEST measure was administered weekly for the duration of treatment, and at 2 month follow-up. The CORE-OM was administered at four points: pre-treatment, half way through the treatment, post-treatment, and at 2 month follow-up. In addition, the participants were asked to complete The Service User Satisfaction Survey and the STEPPS Evaluation Survey after their last session of the STEPPS programme. As already mentioned both surveys included the multiple-choice questions alongside a series of open-ended questions, requesting textual responses. After gathering the results, qualitative data from the open-ended questions was tabulated and the textual responses were collated for further analysis. This data was then analysed using Thematic Analysis approach (Braun & Clarke, 2006). The first step involved reading and re-reading the data several times in order to facilitate immersion and familiarity with the data set. Following on from this, the data was coded according to the main issues considered to be pertinent to the research question. The third stage involved searching for themes within the data and combining different codes that shared common patterns. At this stage the themes that were too diverse or did not have enough data to support them were discarded (Braun & Clarke, 2006). Each theme was then named in order to convey its essence. Finally, a selection of citations from the participants was chosen to provide a lucid example of the main issues identified within each theme (Braun & Clarke, 2006).

Ethics

The study was assessed and approved by the University of Bath Psychology Department Research Ethics Committee. The local NHS Research & Development (R&D) office was consulted regarding the need for any additional ethical approval for the study. Due to the fact that the data was collected as an integral part of the service evaluation, and did not require any additional time or activity on the part of the participants, this was regarded as a service evaluation project and not subject to prior ethical approval from the R&D. All participants gave consent to allow outcome data to be used to evaluate the effectiveness of the group. Participants were informed that at any point they could withdraw consent.

Results

BPD symptoms

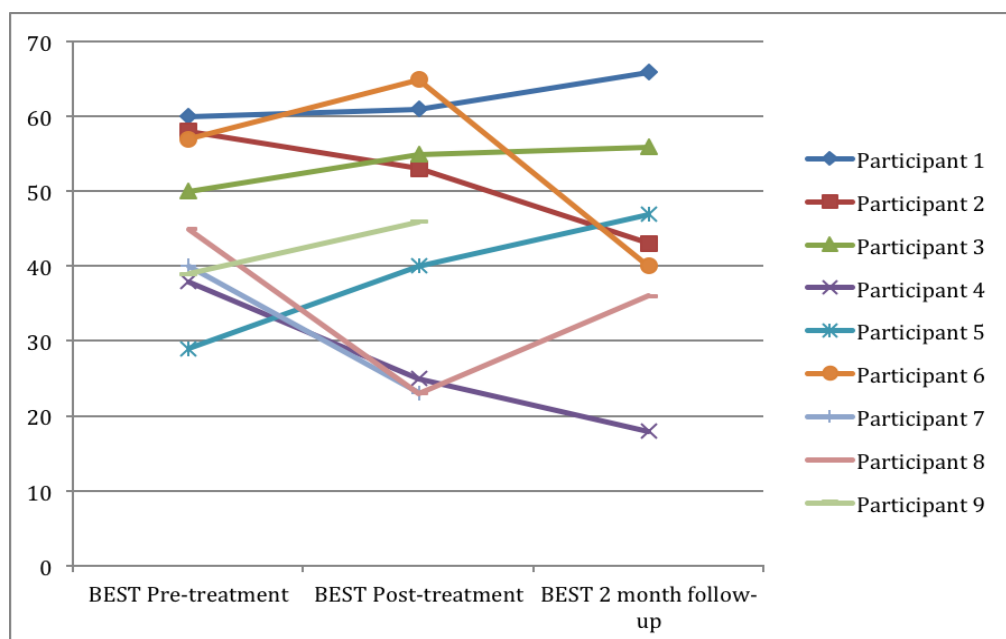
The results of the descriptive statistics are summarized in Table 1. below. The Wilcoxon Signed-Rank test was conducted to compare changes in participants' mean scores from pre to post-treatment, and follow up. The results indicated that the STEPPS programme did not elicit a statistically significant change in BPD symptoms from pre to post-treatment, $Z = -.356$, $p = 0.722$. Similarly, the STEPPS programme did not elicit statistically significant changes in the participants' BPD symptoms from pre-treatment to 2 month follow-up, $Z = -.507$, $p = 0.612$.

Table 1. Descriptive statistics for the BEST and CORE measures from pre to post-treatment and follow-up.

| Measure | Mean score (SD) | Range |
|-------------------------------|-----------------|--------|
| BEST pre-treatment | 45.1 (SD=9.5) | 29-58 |
| BEST post-treatment | 43.4 (SD=16.5) | 23-65 |
| BEST 2 month follow-up | 43.7 (SD=15.2) | 18-66 |
| CORE pre-treatment | 83.1 (SD=14.5) | 67-110 |
| CORE post-treatment | 76.5 (SD=28.8) | 41-114 |

Visual analysis of data was used to interpret and draw inferences from data collected during the study. With regard to changes in symptoms of BPD, visual inspection of data presented in Graph 1 revealed no clear treatment effects or trends. Although there were some individual differences, as a group participants did not appear to improve.

Graph 1. Changes in the BEST scores from pre to post-treatment and follow-up for each participant

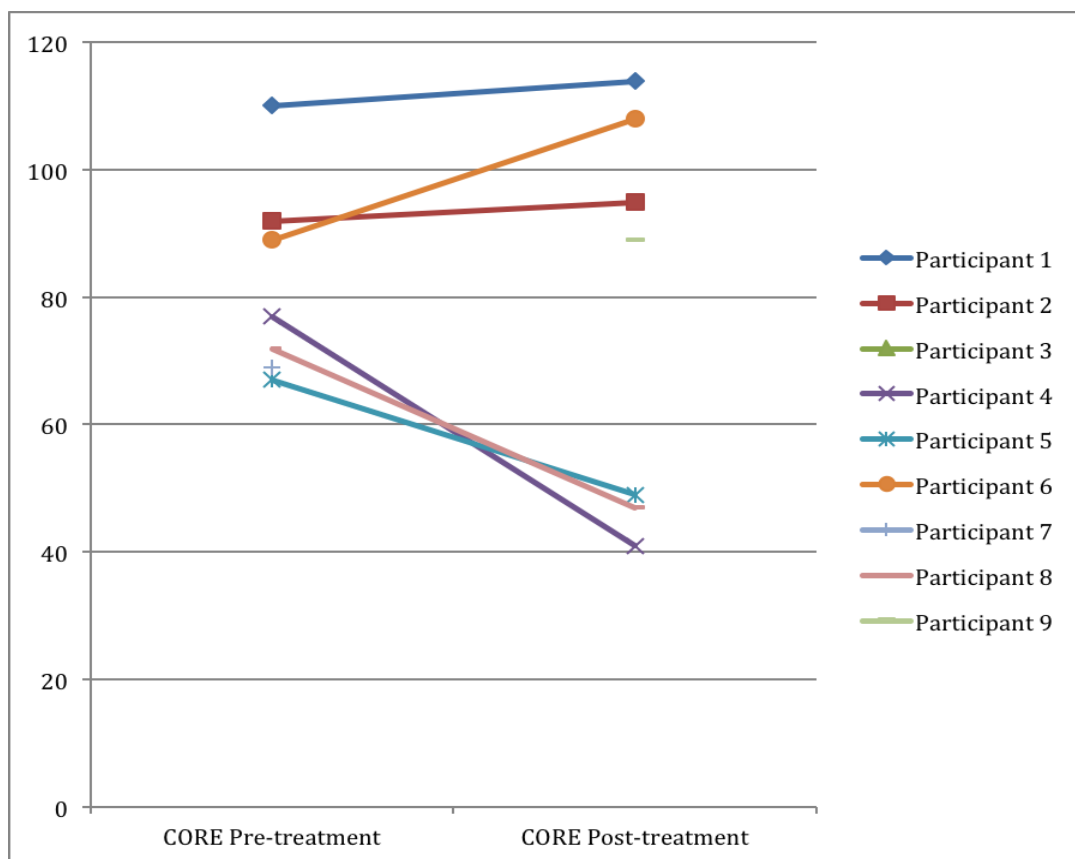


Psychological distress and functioning

As for the changes in psychological distress and functioning, the results of the Wilcoxon signed-rank test indicated that the STEPPS programme did not lead to statistically significant improvement in participants' global distress measured on CORE-OM from assessment to end of treatment, $Z = -.734, p = 0.463$.

This was consistent with the visual examination of graphed data indicating no reliable or consistent pattern that would indicate positive effects of the intervention for the group as a whole (Graph 2.). Instead, it appears that three individuals improved, two indicated slightly higher distress and one remained unchanged following post-therapy. Therefore, the use of visual inference and statistical procedures found no benefits on BPD and distress related measures from pre to post-treatment.

Graph 2. Changes in the CORE-OM scores from pre to post-treatment for each participant



Please note: pre and post-treatment data for participant 3 is missing; participant 7 reported only pre-treatment scores, while participant 9 reported only post-treatment scores.

Participants' satisfaction with the STEPPS treatment

Seven out of nine participants (77%) responded to the STEPPS Treatment Evaluation Survey. Overall, the results indicated high satisfaction with the STEPPS treatment ($M=47.2$, $SD=4.8$), with 60 being the maximum score. All participants reported attending more than half of the sessions, with the overall attendance rate of 77%.

Structure

Length of sessions

All participants reported that the STEPPS programme was too short, and five out of the seven indicated that the time given to learn new skills was insufficient.

Materials used in sessions

The results indicated varying results regarding the amount of material covered in the STEPPS programme. More specifically, four of seven people reported that there was too little material used in sessions, two considered it too much, as one was satisfied with it.

Discussion of intense emotions

Similar discrepancy emerged with regard to the time allocated to discussing intense emotions. More specifically, four people felt that there was too much time spent on discussing difficult emotions, one person felt it was not sufficient, another individual thought there was enough information, and four felt it was too much.

Skills

All participants reported that they were given a clear explanation of what BDP means, and they considered the manual a helpful part of their treatment. Moreover, six participants reported that the skills learned in therapy were highly effective and taught them how to handle their difficulties better. For instance, three participants reported that they have been much less likely to harm themselves after undertaking the STEPPS programme, however another three were neutral, and one person reported no difference in their self-harming behaviour.

Satisfaction with services survey

Information provision and communication with the service

Seven out of nine participants (77%) completed The Service User Satisfaction Survey. Overall, the results suggested high satisfaction with the experiences of the service concerned ($M=50.8$, $SD=11.8$). With regard to information provision, three of out the seven participants reported high satisfaction with the information they were given on what to expect before their treatment, and the method of receiving this information (e.g. appointment letter, phone calls). Moreover, four participants felt that the written communication from the service was clear and effective. However, two participants reported dissatisfaction with the service received at the reception.

Use of questionnaires

As part of the routine practice and evaluation of outcomes, all participants were asked to fill in a number of questionnaires at various stages in their treatment. Four participants reported that they were given satisfactory reasons for completing the questionnaires (67%), while two were uncertain.

Satisfaction with waiting times

The available data on waiting times was poor and did not enable calculations of an average waiting time. However, the reported waiting times varied from less than a month to 6 weeks for an assessment, and between a few weeks to 3 months for treatment. Three out of the seven participants were dissatisfied with their waiting times, and the information they received about waiting times. However, another three participants were very satisfied with their waiting times and information regarding this.

Satisfaction with treatment

All participants reported feeling respected and listened to by their therapists. Four out of the seven participants (67%) reported that they felt involved in choices about their treatment, and felt that their goals and expectation at the start of the group had been met. Two out of the seven participants (33%) users felt that the help provided at the clinic allowed them to resolve their main problem.

Qualitative Results

Four overarching themes were identified from data: (1) Change in therapy; (2) The role of therapeutic alliance; (3) Ideas for improvement; (4) Therapy endings. Sub-themes were evident within each of the overarching themes. These will be described in turn, and illustrated with relevant quotations. For the purpose of confidentiality all names have been removed from quotations.

Theme 1. Change in therapy

One of the most prevailing themes was related to the change in therapy and ‘personal benefits’ of taking part in the STEPPS group. All participants saw therapy as being characterized by the process of talking about their difficulties with others, feeling accepted and understood. This overarching theme breaks down into three sub-themes: Feeling cared for and understood; Improved coping skills; and Personal benefits.

i. Feeling cared for and understood

All participants spoke of a sense of feeling safe, supported and understood, as one of the main benefits gained from therapy. This is illustrated in the following quotes:

“This has been the most effective treatment I have had so far. A group environment has made me feel as if other people understand me”.

“I have never met such an incredible bunch of people. Everyone has made me feel so welcome”.

Moreover, many participants said that they felt that they fit in and belong, which reduced their feelings of loneliness and feeling different.

“It has been the first time in so long that I’ve found a group where I feel I fit in”.
“Everyone is so similar but also different. I no longer feel alone or weird”.

ii. Improved coping skills

Moreover, many participants reported a number of positive changes that resulted from their participation in the STEPPS group. This included improvements in communication skills, emotions management, and reduced self-harm.

“I have pondered about self-harm and have been very close to it but I have not, but I do feel that I can trust myself not to self-harm when I spin into crisis”.

“This is the first time I feel I have been given help to help myself”.

The quote above seems to capture a sense of agency and self-efficacy for managing personal difficulties.

iii. Personal benefits

The number of common themes emerged when participants were spoke of benefits of therapy. Many participants reported a number of changes including being more able to deal with their problems, and cope with extreme feelings and thoughts, feeling happier, and being less judgmental towards themselves.

“I have stopped exploding and seem to keep calm. Also have stopped judging myself most of the time”.

“I felt I had people to go to and I have been able to question unhelpful thoughts”.

Furthermore, one person also reported reduced symptoms of psychosis and trauma flashbacks.

“Psychosis has hugely reduced. My trauma flashbacks used to haunt me all day but now they don’t”.

Theme 2: The role of therapeutic alliance

A number of participants commented that they valued hard work from the group facilitators and appreciated their therapeutic style characterised by approachability, feeling safe and understood.

“The facilitators enabled the group safety and support so we have been very positive to each other”.

However, the group felt that if possible, future groups should avoid change of group facilitators, as this may have a detrimental effect on the cohesion and continuity of the group.

“I (...) would strongly suggest that therapist do not change during the course as you have built up trust and then someone else comes in and could make things difficult. Also it is not good for the therapist as they don't get the consistency or get to see how much their hard work is paying off”.

Theme 3: Ideas for improvement

The third overarching theme was “Ideas for improvement” with four sub-themes as follows.

i. More time to consolidate skills

The majority of the people felt that the course was not long enough and did not allow for consolidation of new skills, as illustrated below:

“This course has been extremely helpful. I’m totally positive. Any criticism would be that not enough was given to each skill”.

“Maybe the weekly meetings could be lengthen by half an hour, so more time is spent on the skills and ways of implementing them, so a better understanding”.

ii. Specific topic of interest

Moreover, the participants identified a number of topics that they would like to explore in

more depth during the session. This included the issues around schema work and filter, specific skills about positive spins, problem solving, and dealing with relationships difficulties and abuse.

iii. Involve the support system around the person

Another sub-theme related to involvement of reinforcement team as well as the need for more support from care-coordinators. In particular, the service users reported that involving family and friends would be beneficial, and could happen more frequently and earlier on in their treatment.

“I feel it would be beneficial for the evening session with our reinforcement teams, be organised for within the first 4 weeks, with date set out at the start of the group. As I feel I am not utilising my reinforcement team correctly, as I don’t think I fully understand their role”.

While many participants commented on the usefulness of the support from their family and friends, some did not fully understand their role in treatment, and how to fully utilize this source of support.

iv. Reduce paper work and allow more time for discussion

The group also found the amount of paper work overwhelming, and spoke of their preference of having more time for discussion and taking own notes. Some participants also noted a detrimental effect of being overwhelmed with paperwork and how this could lead to sense of failure.

“I felt that the level of paper work and homework could potentially put some people off. Some weeks had so much homework it was off putting and was a struggle to do, as lack of time due to just trying to survive the week. This does not help if you are constantly judging yourself, which could lead to a negative reaction”.

Theme 5: Managing therapy endings

The feedback also pointed out to the need for more careful consideration of discharge planning and therapy “endings”, as premature termination of services or support from care coordinators may contribute to a relapse.

“Do not just cut off treatment after 20 consecutive weeks, it can be very harmful (...). This is extremely dangerous and such a waste of time of all the hard work and support the psychologist gave us (...)”.

Discussion

The present study was intended to evaluate clients' satisfaction with services and outcomes associated with the introduction of the STEPPS programme within the UK secondary care services. Of particular interest was the finding that qualitative and quantitative analysis appeared to yield contrasting results. More specifically, the preliminary evaluation of the quantitative data indicated no changes from pre to post-treatment and 2 months follow-up. Thus, the results of this investigation suggested that the STEPPS program did not lead to significant and clinically meaningful improvements in symptoms of BPD, mood and functioning. This is in contrast to the previous research (Blum et al., 2002; Blum et al., 2008; Black et al., 2008). The qualitative findings from this evaluation suggested a range of positive outcomes for the participants. In particular, the results indicated that the program was well received by participants, and resulted in a number of qualitatively reported positive changes following the group, such as improved emotions management, better communication skills, and more positive relationships with others. Moreover, all participants reported high satisfaction with their experience of the STEPPS programme, and the service concerned.

There are a number of possibilities that could account for this apparent discrepancy in the results. Firstly, some deterioration of symptoms towards the end of therapy could be perceived as a predictable and understandable response in people with BPD, given their difficulties managing endings (Blum et al., 2002) although there was no sign of a “bounce back” at follow up. Secondly, the difference between qualitative and quantitative findings may reflect limited sensitivity of the outcome measures used in identifying more subtle changes in symptom severity, although this measure was designed for the purpose of evaluating this programme. Thirdly, the improvements reported by the clients in their qualitative accounts could be related to the non-specific therapy factors or process variables that have not been assessed in this evaluation. It is also possible that the process of change in such severe cases would be slower and more gradual than in previous studies, and may not be reflected adequately in the time concerned. This is possible given that severity and complexity of our sample was much higher compared to the previous research

(Black et al., 2008; Blum et al., 2008). For instance, Black et al. (2008) in their study of twelve female offenders with BPD, reported a mean score for BEST was 28 at baseline, which decreased to 16.9 post-treatment (Black et al., 2008). Similarly, Blum and colleagues in their RCT reported the mean score on BEST measure of 39, which decreased to 31.8 post-treatment (Blum et al., 2008). In contrast, the mean severity score on BEST measure in our study was 46.3, which decreased to 43.5 post-treatment. This suggests, that the severity scores were higher in our sample as compared to previous research (Black et al., 2008; Blum et al., 2008), which might explain the smaller changes in severity of BPD observed in this study. Furthermore, this study demonstrates the difficulties translating the results of available RCTs and research trials into real world clinical setting often characterised by complex and comorbid presentations.

Finally, and most likely, the results may indicate that the programme was not effective, and the qualitative data reflect demand characteristics. Although participants reported that the program taught them new skills to better manage their disorder, this did not translate in clinically meaningful changes on measures used to evaluate the implementation of the STEPPS programme. Thus, it is possible that the results from the qualitative evaluation of this study were inflated due to participant knowing that the scores would be observed by the therapist. In particular, it is possible that positive outcomes reported in the qualitative feedback were due to the effects of social desirability and demand characteristics bias. While the participants reported improvements, those benefits might have resulted from extra social support, hope and therapeutic alliance received through the programme. These elements have been shown to be particularly important for people with BPD due to their histories of invalidating and unreliable environment and social relationships (Linehan, 1993). Alternatively, they could have occurred due to desire to report positive findings to please the therapist, and not the elements specific to STEPPS. Therefore, the results of this study does not provide support for the notion the STEPPS programme is a reasonable treatment option for complex cases presenting in the UK secondary care services.

Limitations of the present evaluation

However, it is important to acknowledge limitation of this study. Firstly, the results of the present evaluation are mixed and should be treated with caution. In addition, it is important to note that the generalizability of the findings is limited by a small sample size that consisted of females, who presented to the UK secondary care services with severe symptoms of BPD. Therefore, these results may not generalise to other populations or services. Finally, due to the lack of statistically significant changes from pre to post-

treatment, and lack of active comparison group, this study does not allow conclusions about the efficacy of the STEPPS programme, or its effectiveness relative to other manual-based treatment programs, such as DBT or CBT. More research is warranted to further evaluate the value of the STEPPS group in secondary care services.

Recommendations

The finding that the relative lack of change in quantitative measures was inconsistent with the qualitative findings is of particular importance, when considering future evaluation of services. The following section will discuss the main implications of the present evaluation, and how this could be applied in terms of service improvement.

- ***Recommendations for future STEPPS groups***

Consider further evaluation of the STEPPS programme

As the implementation of the STEPPS programme did not result in significant pre to post-treatment improvements, it is crucial for the service to carefully consider future delivery of this treatment. Given the present findings obvious recommendation is that first and foremost, first and foremost, it is important not to assume the effectiveness of the STEPPS programme. Therefore, any continuation of STEPPS should include evaluation.

For instance, the service could consider offering another STEPPS group tailored specifically for people with lower severity of BPD symptoms. Secondly, the service could use alternative outcome measures, such as goal-based outcomes, or measures related to coping and quality of life, as those factors may be more meaningful and mineable to change in more both severe and less severe cases.

Follow-up data

Due to lack of long-term outcome data in this study, it was not possible to establish the impact of the group on symptoms and functioning past 2 months. If possible, the service could consider collecting follow up data at 6 or 12 months.

Offer STAIRWAYS to consolidate skills and prepare for therapy ending

Service users felt that it would be helpful to have more time to consolidate their skills and retain a link with the service and/or other service users. Therefore, the service could consider introduction of STAIRWAYS programme designed to maintain the skills learned in STEPPS (Blum et al., 2002). This would also facilitate graded discharge from treatment

and better management of therapy endings and fear of abandonment commonly experienced by people with BPD (Blum et al., 2002).

Avoid changes of group facilitators

According to NICE (2009), staff working with service users presenting with BPD features, need to be careful in their handling of the therapeutic relations, particularly regarding attachment issues. Based on feedback from the service users, transition from one therapist to another during the group was perceived as difficult and potentially threatening to the consistency and integrity of the group. In order to maintain consistent provision of care, the change of group facilitators should be avoided as far as possible, with the therapists being able to offer a reliable time commitment prior to the group.

- ***General service recommendations***

Offer choice and cooperation

In terms of more general recommendation, it is important to offer choice and cooperation in all aspects of service users' experience of the services. According to the NICE guidelines (2009) active involvement of service users in every aspect of their treatment is a crucial aspect of engagement. Therefore, service users should be involved as much as possible in making informed decisions about their treatment. The service should consider active ways of engaging service users, and should continue with their approach of offering an opportunity to discuss their treatment options in the initial appointment.

Communication and management of the waiting times

A clear and consistent communication is crucial to the engagement with services and should be considered at every stage of therapy process. In particular, in the event of a delay in assessment or treatment, the service should consider communicating the reasons for a delay, and consider signposting clients to other sources of support if appropriate.

Promote further involvement of service users' families, partners and carers

According to NICE guidelines it is crucial for the service to actively involve clients and their family, partners and carers in enhancing and improving service provision (NICE, 2009). This is consistent with the views of the participants from the present study who reported that they valued input from their families and felt that this could have been introduced earlier on in their treatment. Therefore, it is recommended that the service

should consider offering more sessions to family and support systems and introduce them earlier on, subject to client's choice and rights to confidentiality.

Increase availability of care co-ordination

In addition, the service should reconsider access to care coordination during the treatment. Given that distress can often escalate while the person is in therapy, it is recommended that care coordination should be increased during the STEPPS programme to enable adequate support for the participants. This may be particularly important in times of crisis, and during therapy ending.

Managing endings

Since ending therapy is often contentious to many service users, more preparation before therapy endings and/or discharge might be beneficial. Although therapy endings have been carefully planned for before the group started, the service could consider a more structured approach to 'endings' for the future groups. For instance, endings could be introduced earlier on within the programme. Involving service-user's family and support system would also be crucial when planning therapy endings.

- ***Recommendations for further research and evaluation***

Evaluation of the STEPPS programme

Further evaluations of the STEPPS programme are warranted. It would be important to compare the results of the present study with findings from other evaluations of the STEPPS programme in order to fully assess its efficacy, and establish who is most likely to benefit from it.

Comparison with different approaches

Although promising from a qualitative perspective there is a need for further research comparing STEPPS programme to other treatment options for BPD to investigate whether similar outcomes can be obtained using more cost effective and less intensive model of STEPPS treatment.

Development of outcomes measures

It is recommended that future research should consider exploring other ways of assessing outcomes of interventions for people with BPD. It is possible that existing measures used

to assess changes in BPD may not adequately capture service user experience of change and changes that happen as a result of therapy process. Moreover, agreeing on a set of outcome measures for future studies on BPD would enable to compare the effects of different interventions and contribute to developing evidence base treatment guidelines for people with BPD (NICE, 2009).

Developing a care pathway

A future research or service evaluation could also consider using mixed-method study examining the care pathway of people with BPD, such as factors affecting management of care, and transfer between different components of care (e.g. referral from primary to secondary care, management of endings and discharge from services). Such a study should ideally include collection and analysis of both qualitative and quantitative data as recommended by NICE (2009).

Summary and conclusion

Overall, the present study suggests that the implementation of the STEPPS resulted in some positive changes as indicated by the qualitative findings of this study. This however has not been substantiated by the quantitative results indicating lack of statistically significant changes in symptoms of BPD and distress following the STEPPS groups. This finding is of great relevance when considering future evaluation of treatment outcomes for people with BPD, and participants' satisfaction with services.

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Main research project paper

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|------------------------------|---|
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Abstract

Objective: The present study sought to investigate the extent and role of health anxiety, mental defeat, self-compassion and health related coping behaviours in relation to fear of cancer recurrence (FCR), psychological distress amongst breast cancer survivors, according to whether or not they had had chemotherapy as part of treatment. This comparison was carried out to build upon previous research findings that have pointed an especially adverse psychological impact of chemotherapy treatment.

Methods: A total of 77 breast cancer survivors were recruited, and completed questionnaires in order to investigate whether more intensive treatment (i.e. including chemotherapy alongside radiotherapy and surgery) will be associated with higher levels of health anxiety, mental defeat, fear or recurrence, and psychological distress.

Results: Group comparison demonstrated significantly higher levels of health anxiety, FCR, mental defeat and psychological distress amongst patients who have undergone more chemotherapy. Multiple regression analysis indicated that health anxiety, psychological distress and age, were the strongest predictors of fear of recurrence; while mental defeat and fear of recurrence were strongest for psychological distress. In addition, mental defeat was inversely associated with higher self-compassion.

Conclusions: These results suggest that FCR, health anxiety and mental defeat is significantly elevated amongst breast cancer survivors, in particular those who have undergone chemotherapy, and is associated with increased levels of longer-term psychological distress. Cognitive-behavioural interventions, which target these variables, should be evaluated in these patients.

Introduction

Increasing incidence of cancer, an aging population, and advances in early detection and treatment mean that the number of people living with and surviving cancer is on the rise and currently totals around 1.8 million in the UK (Department of Health, 2012; Maddams, Utley & Møller, 2012). Whilst many cancer survivors adjust relatively well following the completion of active treatment (Boyes, Girgis, D'Este & Zucca, 2012), there is evidence that a significant proportion continue to struggle, often for many years, with a range of unmet psychological, social and physical needs (Armes, Crowe, Colbourne et al., 2009; Donovan, Thompson, & Jacobsen, 2012; Santin, Mills, Treanor & Donnelly, 2012). Accordingly, research surrounding cancer 'survivorship' has gained prominence internationally in recent years, driven in the UK by the National Cancer Survivorship Initiative (NCSI; Department of Health, 2013). In the present paper, we consider the empirical and theoretical understanding of psychological distress in cancer survivors.

Cancer is known to have a profound psychological and emotional impact, with the prevalence of major depression and anxiety disorders two to three times higher than in the general population (Boyes, Girgis, D'Este & Zucca, 2011; Stark & House, 2000; Kessler, Wai, Demler & Walters, 2005; Levin and Alici, 2010; Miller & Massie, 2010; Pirl, 2004). Furthermore, up to 47% of cancer survivors express a fear of cancer recurrence (FCR; Department of Health, 2012), defined as the fear that cancer will recur or progress in the same or a different part of the body (Koch, Jansen, Brenner & Arndt, 2013). It has been suggested that managing FCR is one of the most common and pronounced challenges of cancer survivors (Koch et al., 2013). Although a degree of fear about disease relapse is, of course, entirely understandable and proportionate following cancer treatment, it can often become excessive, persistent and significantly disabling in terms of high levels of psychological distress and an associated adverse impact on quality of life (Crist & Grunfeld, 2012). Several recent systematic reviews have summarised the evidence in relation to the factors influencing FCR (e.g. Crist & Grunfeld, 2012; Koch et al., 2013, Park et al., 2013; Simard, Thewes, Humhris et al., 2013). The factor most consistently associated with increased FCR has been younger age, whilst other socio-demographic indices (e.g. gender, education, employment) have not proved influential. With regard to medical and treatment-related factors, there have been reported differences across cancer types, with breast, colorectal and lung cancer associated with greater FCR (Simard, Savard & Ivres, 2010). Perhaps surprisingly, stage of disease has not emerged as a reliable predictor of FCR (Crist & Grunfield, 2013). By contrast, treatment type has been linked

with higher levels of FCR, with chemotherapy reported to be associated with greater FCR amongst breast cancer survivors (e.g. Constanzo et al, 2007; Janz, Hawley, Mujahid, et al., 2011; Lasry & Constanzo, Lutgendorf, Matters, et al., 2007; Mehnert, Berg, Henrick, & Herschback, 2009). However, other studies with a range of cancer types found no relationship between treatment type and fear of recurrence (Leake, Gurrin, & Hammond, 2001; Rogers, Scott, Lowe, Ozakinci, & Humphris, 2010). Therefore, the evidence remains mixed and often contradictory overall in relation to the influence of treatment type on FCR (Crist & Grunfeld, 2013), and it is therefore important to further investigate and clarify these relationships. Much stronger evidence exists for associations between physical symptoms (e.g. pain, treatment side effects, fatigue) and elevated FCR (Crist & Grunfeld, 2013), which might often be driven by the misattribution of benign somatic cues to cancer recurrence or progression. In turn, protracted FCR could serve to heighten awareness and vigilance of physical symptoms, thus compounding and reinforcing worry and anxiety (Simard et al., 2013). Indeed, a number of authors have emphasised the relative importance of cognitive and emotional factors as opposed to medical or demographic factors in maintaining FCR, prompting suggestions that the subjective experience of the disease might influence FCR to a greater degree than its objective severity (Koch et al., 2013; Simard et al., 2013).

Lee-Jones, Humphris, Dixon and Hatcher (1997) presented a cognitive formulation of FCR in a short review paper, proposing the role of internal (e.g. symptoms, somatic cues) and external (e.g. hospital appointments, magazine articles) stimuli in activating intrusive thoughts and FCR. Both Lee-Jones et al. (1997) and a recent mindfulness-based intervention study (Lengacher et al., 2014) proposed FCR as a mediating variable, in turn influencing psychological distress and behavioural responses. Lee-Jones et al (1997) posited that likely behavioural responses of FCR might include excessive physical self-examination and reassurance-seeking from health professionals. This is consistent with recent preliminary evidence suggesting that greater FCR was associated with higher frequency of unscheduled visits to GP, body self-examination, avoidance of formal cancer screening and more use of counseling and complementary therapy services (Lebel, Tomei, Feldstain et al., 2013; Thewes, Butow, Bell, Beith et al., 2012). Interestingly, Thewes et al., (2012) found evidence that higher FCR was associated with excessive self-monitoring (e.g. checking body parts for cancer) but less frequent use of formal, prescribed, health practitioner administered cancer screening examinations. This is consistent with the cognitive-behavioural model of health anxiety, which proposes that high levels of health anxiety are associated with both excessive threat monitoring and avoidance behaviour

(Salkovskis et al., 2003; Warwick & Salkovskis, 1990).

Although the cognitive-behavioural model of health anxiety has been referred to in the FCR literature (e.g. Lee-Jones et al., 1997; Thewes et al., 2012), its propositions have not been empirically investigated in the context of cancer survivorship. According to the model, people who experience severe and persistent anxiety about their health have a relatively enduring tendency to misinterpret bodily sensations and other health related information as signs that they currently have, or are at risk of developing, a serious medical illness (Salkovskis, Warwick, & Deale, 2003). This is of particular interest, as both FCR and health anxiety are characterised by preoccupation with physical symptoms and heightened perceptions of risk of serious illness (or its recurrence). Thus, individuals inclined towards health anxiety could be especially susceptible to developing chronic FCR, driven by hypervigilance to signs of danger, selective attention to threat information, excessive monitoring of their body for signs of cancer, or avoidance of reminders of cancer and treatment (Crist & Grunfield, 2013).

Anxiety is not the only psychological response to cancer. Brennan (2004) has described the attritional experience of living with relentless anxiety and fear of cancer relapse, often resulting in a profound loss of confidence and sense of control, and leading to a withdrawal from valued goals and activities in life. This description resonates with the construct of ‘mental defeat’, which is a relatively recently identified cognitive phenomenon capturing the loss of autonomy and negative self-beliefs prominent in chronic pain sufferers (Tang et al., 2007, 2010). Research in chronic pain patients has identified mental defeat as a powerful predictor of anxiety, depression and psychosocial disability (Tang et al, 2007, 2010). Persistent chronic pain is a major clinical problem affecting 25 to 60% of breast cancer survivors (Andersen & Kehlet, 2011), compounding the already psychologically and emotionally arduous treatment and recovery pathway. Accordingly, the construct of mental defeat might offer important insights into cancer survivorship, particularly in terms of its relationship to other psychological factors such as FCR and health anxiety.

Although psychological distress in people suffering from chronic and life-threatening conditions are highly prevalent (Evans et al., 2005), research into factors that may protect people from developing emotional difficulties remains scarce. Neff (2003, 2009) has defined self-compassion as comprising of three elements: self-kindness, which refers to the ability to treat oneself with care rather than self-judgement; common humanity which refers to a recognition that suffering is a shared aspect of the human experience; and

mindfulness. According to this proposal, individuals who are self-compassionate are more likely to respond with awareness, understanding and self-kindness when faced with difficult life events and emotional distress (Przedziecki et al., 2013). Recent developments in this field have pointed out to self-compassion as a potentially relevant construct in relation to the experience of physical illness (Costa & Pinto-Gouveia, 2010; Wren et al., 2011). Moreover, it has been suggested self-compassion is associated with improved psychological well-being and might be an important factor for fostering emotional resilience (Neff, 2009; Przedziecki et al., 2013). Previous studies highlighted a significant relationship between higher levels of self-compassion and lower depression and anxiety scores (Leary, Tate, Adams, Allen, & Hancock, 2007; Van Dam, Sheppard, Forsyth, & Earlywine, 2011). Self-compassion has also been suggested as an important factor that could enhance adaptive responses to illness, such as emotional self-regulation and adoption of positive health-related behaviours that promote health and well-being (Terry & Leary, 2011). More recently, research evidence indicated the protective role of self-compassion in relation to depression and anxiety, and quality of life in patients with cancer and chronic physical health conditions (Pinto-Gouveia, Duarte, Matos, & Fráguas, 2014). Furthermore, low self-compassion has been found to mediate the association between psychological distress and body image disturbance among breast cancer survivors (Przedziecki et al., 2013). Thus, the construct of self-compassion may offer a valuable insight into protective factors that could prevent one from developing elevated levels of mental defeat and, in turn, severe and protracted psychological distress following cancer diagnosis and treatment.

In summary, despite an increasing research interest in FCR over recent years, the empirical literature remains largely atheoretical in terms of understanding and defining the relationships between key psychological parameters. Existing evidence points towards the importance of subjective interpretations of physical symptoms in provoking intrusive thoughts and FCR, which can then prompt excessive self-monitoring and reassurance-seeking behaviours. Type of cancer treatment has also been found to influence threat appraisals surrounding cancer relapse, although the evidence to date is mixed and inconclusive. Further efforts to elucidate cognitive and emotional factors underpinning FCR offers the prospect of designing targeted cognitive-behavioural interventions, building upon a recent successful trial of CBT for health anxiety in medical settings (Tyrer et al., 2014). To these ends, the present study seeks to investigate the role of health anxiety, mental defeat and self-compassion in relation to FCR and health related coping behaviours.

Aims and objectives

The primary aims of this study were: (1) to investigate the extent to which health anxiety, mental defeat and self-compassion are associated with FCR, psychological distress and dysfunctional behavioural responses including excessive self-monitoring and reassurance-seeking from health professionals; (2) and to explore whether type of treatment is associated with degree of health anxiety, mental defeat, self-compassion, as well as FCR, psychological distress, and health related coping behaviours.

Hypotheses

It was hypothesised that:

1. More intensive treatment (i.e. including chemotherapy alongside radiotherapy and surgery) will be associated with higher levels of health anxiety, mental defeat, fear or recurrence, and psychological distress.
- 2.1 Health anxiety, mental defeat will be positively related to, and will predict FCR (controlling for known confounding variables such as age).
- 2.2 Health anxiety, mental defeat and fear of recurrence will be related to, and will predict psychological distress in breast cancer survivors.

In addition, the current study included the following exploratory hypotheses:

3. Higher levels of self-compassion will be negatively associated with mental defeat and psychological distress.
4. Higher levels of FCR and health anxiety will be associated with increased maladaptive health related coping behaviours.

Methods

Design

This study utilised a cross-sectional questionnaire design to explore the influence of health anxiety, mental defeat and self-compassion on levels of FCR, psychological distress, and reassurance-seeking health behaviours amongst a sample of breast cancer survivors. The study also examined differences in the above variables between participant groupings according to treatment protocol.

Participants

Participants included 77 female breast cancer survivors (mean age $M=54$, $SD=9.7$, range

34-84), who were recruited through an advertisement on the Macmillan Cancer Voices network, and follow-up review clinics at the Oncology Centre in the Royal United Hospital in Bath, Breast Cancer Centre in the Southmead Hospital in Bristol, and Great Western Hospital in Swindon. For the purposes of this study, 'breast cancer survivor' was defined as a person who has had a diagnosis of breast cancer and has completed primary treatment with curative intent and was presently clear of disease.

Inclusion criteria were: (1) aged 18 or over; (2) confirmed past diagnosis of breast cancer (Stages 0-III); (3) completed primary treatment with curative intent; (4) patients may still be in receipt of treatment to reduce the risk of disease relapse (e.g. hormonal treatment) or for cosmetic reasons related to breast reconstruction surgery; (5) no time limit was set for the time since diagnosis.

Exclusion criteria were: (1) patients who lack capacity to consent to participation (e.g. due to dementia, learning disability, or other cognitive impairment).

In line with the study aims and hypotheses, patients were divided into two groups according to their primary treatment protocol to permit between-groups analyses, as follows: (1) surgery; surgery + radiotherapy; (2) surgery + chemotherapy; surgery + radiotherapy + chemotherapy. The above groups had been arranged in order of increasing treatment intensity and invasiveness, guided by the existing research literature and consultation with local Consultant Oncologists.

Measures

Demographic and clinical characteristics

Participants were asked to provide information about their age, level of education, relationship and employment status. Concerning breast cancer diagnosis, participants indicated time since diagnosis, time since completion of treatment, and type of treatment.

Health Anxiety

Health anxiety was measured using the *Health Anxiety Inventory – Short Form* (HAI-SF; Salkovskis, Rimes, Warwick & Clark, 2002). The HAI is a short 14 item self-report questionnaire measured on a 0 to 3 scale with higher scores indicating higher levels of health anxiety. The HAI-FS is a reliable and valid measure with comparable psychometric

properties to the full-length scale, good internal consistency and test-retest reliability (Salkovskis et al., 2002).

Mental defeat

Mental defeat was measured on adapted version of The *Pain Self Perception Scale* (PSPS; Tang, Salkovskis, & Hanna, 2007). The original PSPS assesses perceptions of defeat associated with a recent episode of intense pain. It includes 24 item rated for their applicability during the pain episode. The higher scores represent the higher levels of mental defeat. The PSPS was adapted to measure mental defeat in cancer survivors in response to their experience of cancer.

Self-compassion

Self-compassion was measured using the 12-item Self-Compassion Scale - Short Form (SCS-SF; Raes, Pommier, Neff, & Van Gucht, 2011), which has good psychometric properties and a near perfect correlation ($r = .97$) with the long form. Internal consistency reliability of the measure is $\alpha = .86$. The SCS-SF is composed of 12 items measured on a 5-point Likert scale, ranging from 1 (almost never) to 5 (almost always). The higher scores represent the higher levels of self-compassion. This scale comprises a positive component that includes self-kindness, common humanity and mindfulness subscales; and a negative one comprising of self-judgment, isolation, and over-identification.

Fear of cancer recurrence

The *Fear of Cancer Recurrence Inventory-Severity Subscale* (FCRI-SS; Simrad & Savard, 2009) is a 9 item scale that was used to measure the presence and severity of intrusive thoughts associated with FCR. The FCRI-SS is derived from The Fear of Cancer Recurrence Inventory that is a comprehensive, multidimensional scale with high internal consistency (Cronbach's $\alpha = 0.95$) and good test-retest reliability, and is intended for use with all cancer patients (Simrad & Savard, 2008, 2009). Responses are rated on a 4-point Likert scale. The scores range from 0-36, with the higher scores representing higher levels of FCR. The cut-off score of 13 on the FCRI Severity Subscale was associated with optimal sensitivity (88%) and specificity (75%) rates for the detection of clinical levels of FCR (Simrad & Savard, 2009).

Psychological distress

Depression

The PHQ-9 (Kroenke, Spitzer & Williams, 2001) is a valid and reliable self-report inventory that was used as a screening tool for severity of depression. The PHQ-9 total score for the nine items ranges from 0 to 27 with higher scores indicating higher levels of depression.

Anxiety

The GAD-7 (Spitzer et al., 2006) is a 7-item scale that was used as a screening for generalised anxiety disorder. A total score for the seven items ranges from 0 to 21, with higher scores representing higher levels of anxiety. The measure has good psychometric properties with sensitivity of 0.89 and specificity of 0.82 (Spitzer et al., 2006).

Health related coping behaviours

Following Thewes et al. (2012), five single-item questions were employed to assess: (1) the number of times the participants had visited their GP and Oncologist or Specialist Nurse to discuss potential symptoms of recurrence in the past 12 months; (2) the number of GP visits for any reason in the past 12 months; and (3) the frequency of breast or body self-examination. In addition, two single-item questions related to (4) the use of the Internet and (5) verbal reassurance from significant others were also included.

Procedure

Suitable participants were identified in liaison with the cancer service clinicians. Consultant Oncologists and other clinical staff assisted in identifying eligible participants. A study advertisement was also posted on Macmillan Cancer Voices website. The participants willing to take part in the study were provided with an information sheet, consent form, questionnaire pack and a pre-paid envelope to be returned to the researcher. Participants were encouraged to contact the research team with any questions or concerns about the study. They were given the option to complete the questionnaire alone or with support from a friend or family member in their home or at clinic.

Analytic strategy

Analyses were performed using SPSS 22 (SPSS Inc. IBM, Chicago, Illinois, USA), with statistical significance set at $p < 0.05$. Data were screened for univariate outliers, missing data and violations to the assumptions of multivariate analysis. Descriptive statistics were

used to describe demographic and clinical characteristics of the sample. As demographic variables, such as age (Simard, Savard & Ivres, 2010)) may influence fear of recurrence, this variable was considered as potential covariates in the analysis. For the type of treatment, an independent samples t-test was performed to examine differences between the two groups on health anxiety, mental defeat, self-compassion, FCR, and psychological distress, and reassurance-seeking health behaviours (hypothesis 1). A series of multiple linear regression analyses was performed to examine the individual strength of health anxiety, mental defeat and self-compassion, and age in predicting FCR and psychological distress (hypothesis 2). These analyses avoided the problem of multicollinearity and permitted a focused evaluation of the key predictor variables of interest in this study. Finally, correlation analyses were conducted to explore the relationship between self-compassion and mental defeat (hypothesis 3), and the relationship between health anxiety, FCR and reassurance-seeking health behaviours (hypothesis 4). In addition, regression analyses were also conducted to explore the extent to which health anxiety and fear of recurrence can account for health related coping behaviours.

Collinearity diagnostics were conducted using the variance inflation factor (VIF) and the tolerance statistics to investigate if the data met the assumptions of collinearity. There are few guidelines that can be applied when interpreting the results of the collinearity diagnostics. If the VIF is greater than 10 then there is cause for concern. If the average VIF is substantially greater than 1 then the regression may be biased. Tolerance level below 0.1 indicates a serious problem, while tolerance below 0.2 indicates a potential problem (Field, 2009). The results of these test indicated that multiple collinearity was not a concern, and that these data were adequate for regression analyses.

Power considerations

A priori power analysis using G*Power (Faul et al., 2009) was calculated and indicated a required sample size of 60, to achieve an effect size of 0.4, power 0.8, alpha 0.05.

Involvement of people with personal experience

People with personal experience of cancer were consulted to ensure that the research protocol, information sheet and questionnaire pack were clear, concise, and acceptable to other patients. Piloting was undertaken with one patient to ascertain feasibility in terms of time needed for participants to complete the questionnaires. This was considered appropriate given the possibility of high levels of fatigue in some cancer survivors.

Governance procedures and ethical considerations

This study was approved by the West of Scotland NHS Research Ethics Committee (REC; Reference: 14/WS/1018), the University of Bath Psychology Research Ethics Committee (Reference: 14-174), and the Research and Development (R&D) Team from the local NHS Trusts involved in data collection.

Results

Demographic and clinical characteristics are presented in Tables 1 and 2 below.

Table 1. Sample demographic and clinical characteristics of the participants

| Variable | Chemotherapy Number (%) | No Chemotherapy Number (%) | All participants Number (%) |
|-------------------------|----------------------------|-------------------------------|-----------------------------------|
| Gender | Female = 53 (100%) | Female = 24 (100%) | Female = 77 (100%) |
| Ethnicity | | | |
| White | 37 (92.5%) | 14 (93.3%) | 51 (92.7%) |
| Asian | 1 (2.5%) | - | 1 (1.8%) |
| Black | 1 (2.5%) | - | 1 (1.8%) |
| Mixed background | - | - | 1 (1.8%) |
| Other | 1 (2.5%) | 1 (6.4%) | 1 (1.8%) |
| Education | | | |
| No formal qualification | 1 (2.5%) | 3 (20%) | 4 (7.3%) |
| Primary | - | 1 (6.7%) | 1 (1.8%) |
| Secondary | 13 (32.5%) | 5 (33.3%) | 18 (32.7%) |
| Diploma | 10 (25%) | 2 (13.3%) | 12 (21.8%) |
| Degree | 8 (20%) | 3 (20%) | 11 (20%) |
| Postgraduate | 6 (15%) | 1 (6.7%) | 7 (12.7%) |
| Other | 2 (5%) | - | 2 (3.6%) |
| Employment status | | | |
| Paid work | 15 (37.5%) | 5 (40%) | 21 (38.2%) |
| Unpaid work | 6 (15%) | 1 (6.7%) | 7 (12.7%) |
| On sick leave | 6 (15%) | - | 6 (10.9%) |
| Unemployed | 2 (5%) | 1 (6.7%) | 3 (5.5%) |
| Other | 11 (27.5%) | 7 (46.7%) | 18 (32.7%) |
| Relationship status | | | |
| Single | 5 (12.5%) | 3 (20%) | 8 (14.5%) |
| In a relationship | 2 (5%) | 1 (6.7%) | 3 (5.5%) |
| Cohabiting | 2 (5%) | 1 (6.7%) | 3 (5.5%) |
| Engaged | 3 (7.5%) | - | 3 (5.5%) |
| Married | 23 (57.5%) | 8 (53.3%) | 31 (56.4%) |
| Divorced | 3 (7.5%) | - | 3 (5.5%) |
| Widowed | 2 (5%) | 2 (13.3%) | 4 (7.3%) |

| | | | |
|----------------------|------------|------------|------------|
| Time since diagnosis | | | |
| Less than 1 year | 3 (5.9%) | 10 (50.0%) | 13 (18.3%) |
| 1-2 years | 13 (25.5%) | 4 (20.0%) | 17 (23.9%) |
| 2-3 years | 11 (21.6%) | 2 (10%) | 13 (18.3%) |
| 3-4 years | 9 (17.6%) | 1 (5%) | 10 (14.1%) |
| 4-5 years | 4 (7.8%) | 2 (10%) | 6 (8.5%) |
| 5 or more years | 11 (21.6%) | 1 (5%) | 12 (16.9%) |

Table 2. Mean and standard deviations of demographic and clinical characteristics

| Variable | Chemotherapy Mean (<i>SD</i>) (Range) | No chemotherapy Mean (<i>SD</i>) (Range) | All participants Mean (<i>SD</i>) (Range) |
|-----------------------------------|---|--|---|
| Age | 51.6 (<i>SD</i> =7.2) | 59.6 (<i>SD</i> =12.4) | 54.0 (<i>SD</i> =9.7) |
| Health Anxiety | 15.8 (<i>SD</i> =6.6) *** (0-42) | 10.9 (<i>SD</i> =6.5) *** (0-42) | 14.3 (<i>SD</i> =6.9) (0-42) |
| Mental Defeat | 16.9 (<i>SD</i> =16.7)* (0-96) | 8.2 (<i>SD</i> =11.7)* (0-96) | 14.2 (<i>SD</i> =15.8) (0-96) |
| Self-compassion | 36.7 (<i>SD</i> =10.5) (12-60) | 40.1(<i>SD</i> =12.8) (12-60) | 37.8 (<i>SD</i> =11.3) (12-60) |
| Fear of cancer recurrence | 20.7 (<i>SD</i> =7.9)**** (0-36) | 14.0 (<i>SD</i> =6.6)**** (0-36) | 18.6 (<i>SD</i> =8.1) (0-36) |
| Depression | 7.2 (<i>SD</i> =6.0)**** (0-27) | 4.1 (<i>SD</i> =4.8)**** (0-27) | 6.2 (<i>SD</i> =5.8) (0-27) |
| Anxiety | 5.0 (<i>SD</i> =4.5) * (0-21) | 2.3 (<i>SD</i> =3.7) * (0-21) | 4.1 (<i>SD</i> =4.5) (0-21) |
| Health related coping behaviours | 7.1 (<i>SD</i> =4.0) | 5.6 (<i>SD</i> =3.3) | 6.7 (<i>SD</i> =3.8) |
| Time since diagnosis (months) | 41.6 (<i>SD</i> =27.7) | 21.1 (<i>SD</i> =18.5) | 36.1 (<i>SD</i> =27.0) |
| Time since treatment end (months) | 33.1 (<i>SD</i> =28.0) | 16.5 (<i>SD</i> =18.6) | 28.9 (<i>SD</i> =26.8) |

SD – standard deviation; * $p<0.005$; ** $p<0.01$; *** $p<0.001$; **** $p<0.0001$

Chemotherapy and no chemotherapy group comparisons (hypothesis 1)

Independent samples t-tests were conducted to compare the chemotherapy with no chemotherapy groups on measures of fear of recurrence, health anxiety, mental defeat, depression and anxiety. The results indicated significant differences between chemotherapy and no chemotherapy group in the scores for health anxiety $t(72) = -3.22$, $p < .001$; fear of recurrence $t(72) = -4.01$, $p < .0001$; and generalized anxiety, $t(70) = -3.27$, $p < .005$.

Levene's test for equality of variances was found to be significant for some variables (mental defeat, depression and total scores for psychological distress). For mental defeat $F(1,72) = 5.64$, $p = .02$, a t-test not assuming homogeneous variances indicated that there was a significant difference in mental defeat observed between the two groups, $t(72) = -2.90$, $p < .005$. Similarly, homogeneity of variance was violated for depression $F(1,72) = 6.50$, $p = .013$. A t-test not assuming equal variances was then calculated and revealed significant differences between two groups on depression scores, $t(72) = -3.76$, $p < .0001$. The groups were also significantly different on the measure of total distress $F(1,72) = 5.48$, $p = 0.02$; $t(72) = -4.16$, $p < .0001$. Finally, the chemotherapy and no chemotherapy groups were not significantly different on measures on self-compassion and health related coping behaviours.

Regression analysis - fear of recurrence (hypothesis 2.1)

A multiple linear regression analysis was performed to examine the individual strength of health anxiety and mental defeat in predicting fear of recurrence; and the strength of health anxiety, mental defeat and fear of recurrence in predicting psychological distress. Regarding fear of recurrence, a significant model accounting for 63% of the variance in fear of recurrence was produced. Health anxiety emerged as the best predictor of fear or recurrence controlling for age, followed by mental defeat, as illustrated in Table 3.

Table 3. Model summary and Beta values for the multiple regression for fear or recurrence variable

| Model | R^2 | Adjusted R^2 | F | B | β | t |
|----------------|-------|----------------|------|-------|---------|-----------|
| Age | .211 | .201 | 19.8 | -.132 | -.157 | -1.994* |
| Health anxiety | .624 | .614 | 60.8 | .720 | .625 | 6.621**** |
| Mental defeat | .646 | .631 | 43.7 | .090 | -.175 | 2.07* |

β – standardized regression coefficient; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; **** $p < 0.0001$

Regression analysis – psychological distress (hypothesis 2.2)

Regarding psychological distress, a significant model accounting for 69% of the total variability in psychological distress was found. Mental defeat emerged as the best predictor of psychological distress, followed by fear of recurrence, as illustrated in Table 4. Health anxiety did not appear to be a significant predictor of psychological distress.

Table 4. Model summary and Beta values for the multiple regression for psychological distress

| Model | R² | Adjusted R² | F | B | β | t |
|--------------------|----------------------|-------------------------------|----------|----------|----------|-----------|
| Mental defeat | .661 | .657 | 146.40 | .416 | .676 | 8.662**** |
| Fear of recurrence | .702 | .694 | 87.150 | .247 | .207 | 1.982* |
| Health anxiety | .703 | .691 | 57.546 | .067 | .048 | .454 |

β – standardized regression coefficient; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; **** $p < 0.0001$

Exploratory findings

Association between self-compassion and mental defeat (hypothesis 3)

A Pearson correlation was calculated in order to explore the relationship between self-compassion and mental defeat. The results indicated a significant negative relationship between self-compassion and mental defeat $r = -.54$, $p < .0001$. Self-compassion was also negatively associated with health anxiety, $r = -.34$, $p < .005$; fear of recurrence, $r = -.33$, $p < .005$; and psychological distress $r = -.502$, $p < .0001$.

Association between health anxiety, fear or recurrence, and health related coping behaviours (hypothesis 4)

A Pearson correlation indicated that health related coping behaviours (e.g. breast and body examinations; Internet use to seek health related information; and reassurance seeking from others) were significantly associated with health anxiety ($r = .51$, $p < .0001$), and fear of recurrence ($r = .52$, $p < .0001$).

Body checking, reassurance seeking, and health related Internet use

A multiple regression was conducted to investigate whether health anxiety, fear of recurrence, mental defeat, self-compassion, age and time since diagnosis could predict the variance in breast and body self-examination. The results indicated that fear or recurrence was the only significant predictor of the variance in the frequency of breast and body examination ($\beta = .34$, $p < .005$), and accounted for about 10% of the variance in body

checking behaviours ($R^2 = .10$, $F(1,69) = 8.95$, $p < .005$).

Health anxiety emerged as the only significant predictor of reassurance seeking ($\beta = .53$, $p < .0001$), and health related Internet use ($\beta = .63$, $p < .0001$). More specifically, health anxiety accounted for 28% of the variance in reassurance seeking behaviours ($R^2 = .28$, $F(1,69) = 26.9$, $p < .0001$), and 40% of the variance in the health related Internet use ($R^2 = .40$, $F(1,69) = 46.2$, $p < .0001$).

The three items (i.e. breast/body examination; Internet use to seek health related information; and reassurance seeking) demonstrated acceptable internal consistency, $\alpha = .65$. The independent samples t-test, revealed that the chemotherapy group reported significantly more use of the Internet for health related information, as compared to no chemotherapy group, $t(72) = -2.73$, $p < .005$. There were no significant differences between the two groups on their body self-examination or reassurance seeking behaviours.

Relationship between fear or recurrence and medical variables

Pearson correlation was calculated in order to establish whether fear of recurrence and health anxiety is significantly associated with medical factors, such as time since diagnosis, time since end of treatment, and duration of treatment. The results indicated that duration of treatment was the only medical variable that was significantly correlated with health anxiety, $r = .24$, $p < .05$. An independent sample t-test was then calculated to examine if chemotherapy and no chemotherapy group differed on duration on treatment. The results indicated no significant differences between the two groups on treatment duration.

Discussion

The primary aims of this study were to investigate the extent to which health anxiety, mental defeat and self-compassion are associated with FCR, psychological distress and health-related coping behaviours; and to explore the impact of type of cancer treatment on psychological outcomes in breast cancer survivors.

Our results indicated that a significant proportion of breast cancer survivors are at risk of experiencing high levels of health anxiety and FCR, with 71% of our sample reporting clinically significant levels of FCR.

Furthermore, we found that women had undergone more extensive treatment including chemotherapy showed significantly higher levels of FCR, health anxiety, mental defeat, and psychological distress. Health anxiety and to a lesser degree mental defeat were the best overall predictors of FCR, when age was controlled for. In addition, mental defeat, and fear of recurrence emerged as the best predictors of psychological distress. Finally, as hypothesized, our results indicated that health anxiety and FCR were significantly associated with health-related coping behaviours (e.g. breast and body examinations; Internet use to seek health related information; and reassurance seeking from others).

These findings highlight the therapeutic value of the cognitive health anxiety model in guiding psychological support interventions for breast cancer survivors struggling with FCR, and are consistent with previous research indicating the usefulness of CBT treatment within medical setting (Tyrer et al., 2014). Although health anxiety has been previously mentioned in the FCR literature (e.g. Lee- Jones et al., 1997; Thewes et al., 2012), to our knowledge, the present study was the first one to specifically and empirically investigate the role of health anxiety in relation to FCR and psychological distress in breast cancer survivors. Furthermore, this study provided evidence for the important role of mental defeat in undermining psychological adjustment following cancer treatment. This is in line with previous studies investigating the role of mental defeat in cancer (Howe, Lagerdahl, & Salkovskis, 2014) and pain-related disability and distress (Tang et al., 2010).

Previous research into FCR has revealed mixed and inconclusive evidence for the impact of treatment type on fear of cancer recurrence and psychological distress (e.g. Crist & Garfund, 2013), although adverse psychological effects following chemotherapy treatment, in particular, have been reported (e.g. Constanzo et al., 2007; Koch et al., 2013; Mehnert et al., 2009). Our study has added further weight to this trend, indicating that women who had previously received more intensive treatment (i.e. including chemotherapy) reported significantly higher levels of fear of recurrence, health anxiety, mental defeat, and psychological distress. It seems highly probable that the longer duration and more severe side effects associated with chemotherapy, as compared to surgery or radiotherapy, results in heightened health related worry and anxiety about recurrence (Constanzo et al., 2007), together with a sense of feeling mentally defeated. Furthermore, chemotherapy treatment can be indicated for patients receiving a less favourable initial diagnosis, and accordingly, this could prompt hyper-vigilance to bodily sensations, which may be more readily interpreted as signs of recurrence (Constanzo et al., 2007).

Interestingly, mental defeat, not FCR, was the strongest and almost the only predictor of distress in our sample. This finding indicates that mental defeat, and its potential impact of sense of self and identity, could be important factor to target in therapeutic interventions for breast cancer survivors. Furthermore, our exploratory results indicated that self-compassion was inversely associated with mental defeat and psychological distress. These findings are in line with other studies reporting self-compassion as a significant predictor of good adjustment and coping with body image concerns amongst women with breast cancer (Przedziecki et al., 2013), and people with other physical health conditions (Costa & Pinto-Gouveia, 2010; Pinto- Gouveia, Duarte, Matos, & Fraguas, 2014). However, correlational data of the type found in the current study do not allow any strong inferences to be made regarding causality. Nevertheless, these findings add to existing knowledge and provide preliminary support for the notion that self-compassion may offer a protective or buffering effect against mental defeat and psychological distress amongst cancer survivors (Pinto- Gouveia et al., 2014; Terry & Leary, 2011).

Limitations

Limitations of the present study include the homogenous nature of the sample: almost all participants were White British, and the vast majority were married and well educated. In addition, data were collected through self-report measures and were based on a self-selected group of women with a history of breast cancer. Due to the focus of this study on FCR, it is possible that women who were experiencing elevated levels of health anxiety and worry about cancer recurrence may have been more likely to participate in such a study. Furthermore, although we found that FCR was the only predictor of breast and body self-examination, it only explained a small amount of variance in breast and body examination, which may not be maladaptive. Finally, it is important to note that although psychological distress measures used in this study (i.e. PHQ-9 and GAD-7) are often used in research in medical setting, they have not been validated for the use with cancer survivors and may not be particularly sensitive for this population.

Research and clinical implications

The present study provides relatively robust evidence for (1) elevated levels of FCR and health anxiety in breast cancer survivors and (2) the importance of mental defeat in predicting psychological distress following cancer, and (3) a potential role of self-compassion as a protective/resilience factor. Prospective studies are therefore needed to identify the extent to which there are causal links between these factors. Furthermore, more

intervention research is warranted for FCR, health anxiety, as well as risk factors, such as mental defeat in cancer survivors. Although research evidence supports CBT as an effective approach for health anxiety in medical setting (Tyrer et al., 2014), this treatment is yet to be evaluated in research trials in cancer survivors. Finally, our study provided preliminary support for the notion that fear of recurrence may mediate the relationship between health anxiety and distress, and that self-compassion could moderate the relationship between mental defeat and distress. However, more research is needed to evaluate this model.

In terms of clinical implications, this study suggests that, in addition to distress, health anxiety, fear of recurrence and mental defeat could be monitored in cancer survivors, as they may contribute to psychological distress and may offer the prospect of designing targeted cognitive-behavioural interventions, and even preventative strategies to address FCR and mental defeat in cancer survivors. Moreover, this study suggests that addressing self-compassion might be a promising intervention for breast cancer survivors struggling with feelings of mental defeat and psychological distress. As mental defeat was an important predictor of levels of distress, it would be important for clinicians to consider that many people may feel ‘defeated’ by their experience of cancer, which can contribute to their distress. Given the self-critical thinking associated with mental defeat, compassion-focused approaches may be helpful to promote more kindness and understanding in response to difficult thoughts and feelings, such as mental defeat.

Conclusions

In conclusion, the present study clearly indicated elevated levels of health anxiety, FCR, and mental defeat amongst breast cancer survivors, particularly in those who have undergone more intensive treatment. Our research provides evidence for the importance of health anxiety and mental defeat with regard to fear of recurrence and psychological distress experienced by breast cancer survivors, and the potential protective role of self-compassion against psychological distress in this population. This provides a sound evidence for further exploration of appropriate clinical interventions targeting FCR, health anxiety, and mental defeat in breast cancer survivors.

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Fear of cancer recurrence and health behaviours in breast cancer survivors: the role of health anxiety, mental defeat and self-compassion.

Background

Increasing incidence of cancer, an aging population, and advances in early detection and treatment mean that the number of people living with and surviving cancer is on the rise. Cancer exerts a profound psychological and emotional impact, with the prevalence of major depression and anxiety disorders two to three times higher than in the general population. Furthermore, up to 47% of cancer survivors express a fear of cancer recurrence, which can often become excessive, persistent and significantly disabling. Therefore, the present study sought to investigate the role of health anxiety, mental defeat and self-compassion in relation to fear of cancer recurrence (FCR), psychological distress and health behaviours amongst breast cancer survivors.

Method

The present study included 77 breast cancer survivors, who were divided into two groups based on their treatment history (chemotherapy vs. no chemotherapy group). Questionnaires were used to assess levels of health anxiety, mental defeat, fear of recurrence, psychological distress, and health related coping. Participants were also asked to provide their demographic and treatment related information.

Results

The results illustrated that breast cancer survivors who had undergone chemotherapy treatment had significantly higher levels of psychological distress, fear of cancer recurrence and health related worries. They were also more mentally defeated by the experience of their cancer, as compared to patients with less extensive treatment.

Our results also show that fear of cancer recurrence can be accounted for by the severity of one's health worries, psychological distress and age (with younger age being associated with more extensive fear of cancer recurrence). In addition, psychological distress, including depression and anxiety, was accounted by the feelings of mental defeat and worries about recurrence. In addition, self-compassion was related to lower level of psychological distress, mental defeat and fear of recurrence.

Conclusions

In summary, this study suggests that fear of recurrence, health anxiety and mental defeat is significantly elevated amongst breast cancer survivors, in particular those who have undergone chemotherapy, and is associated with increased psychological distress. Further efforts to elucidate cognitive and emotional factors underpinning FCR offers the prospect of designing targeted cognitive-behavioural interventions.

Implications for research

- This study investigated the role of fear of recurrence, health anxiety, mental defeat and self-compassion in breast cancer survivors. Further research with different types of cancer is required to explore the contribution of these variables to fear of recurrence in people with other types of cancer.
- More research is needed to test the effectiveness of health anxiety model as a treatment option for fear of recurrence.
- Further research could also explore the protective role of self-compassion and its role in reducing psychological distress and mental defeat amongst cancer survivors.
- More research on the role of mental defeat in cancer patients is needed, including research on therapeutic interventions that could address mental defeat.
- Finally, future research should investigate the differences in chemotherapy types received in terms of psychological outcomes, including fear of recurrence, psychological distress and mental defeat.

Implications for clinical practice

- High level of health anxiety and fear of recurrence reported in this study suggest that screening for clinical levels of fear of recurrence and health anxiety is needed to identify people who may benefit from psychological treatment to address these difficulties.
- Fear of cancer recurrence and health anxiety may be largely unrecognised and untreated amongst cancer survivors. Clinicians should be aware that cancer survivors are likely to present with elevated levels of fear of recurrence and health anxiety, and should consider referral to psychological support, where appropriate.
- More information provision is needed for cancer survivors regarding distress related to worries about recurrence and effective ways of dealing with it.

- Psychological health services should consider collaborating with other professionals to ensure that a clear treatment pathway exists for cancer survivors with clinically significant levels of fear of recurrence.
- Clinicians should be aware of the potential protective role of self-compassion against feelings of mental defeat. Treatment focusing on increasing self-compassion can facilitate psychological well-being amongst breast cancer survivors.
- Health anxiety and mental defeat might well be involved in the development and maintenance of fear of cancer recurrence and psychological distress among cancer survivors, and these factors might be amenable to cognitive behavioural interventions.

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Connecting narrative

Development of research ideas

Prior to my training in Clinical Psychology I had trained as a Clinical Associate in Applied Psychology (CAAP) and developed interest in evidence based treatment, such as cognitive behavioural therapy (CBT), mindfulness-based approaches and trauma-informed treatment models for psychosis. I had also worked as an Assistant Psychologist in Clinical Health Psychology across a range of services including Oncology, Palliative Care, and HIV service. These experiences shaped my current clinical and research interests as illustrated in my research portfolio. During the first year of my training I met with my clinical and research tutors and supervisors who helped me to further develop ideas for potential research projects. Being passionate about improving the well-being of people with physical and mental health difficulties, I strived to develop research ideas that would inspire future research and clinical practice. Therefore, people with mental health difficulties were always in my mind when developing and shaping my research projects.

Review of the Literature

Prior to my training I became particularly interested in the relationship between trauma and psychosis. In order to develop my understanding of the development of psychosis, I decided that it would be interesting to review research into trauma and schemas, and its role in the development of psychosis. When I looked at the literature in this area, I realised that there are a number of existing reviews considering the relationship between trauma and psychosis, however, comparatively less research has been carried out in relation to the role of schemas and trauma in psychosis. Therefore, I decided that this might be an interesting and relevant topic to explore. Following a number of meetings with Lorna Hogg, who helped me to shape and narrow down my ideas, I carried out a literature search to further check the feasibility of this topic. I then decided to focus my review on research investigating schemas in people with psychosis and those with clinical high risk of developing psychosis, with the view to provide directions for further research and clinical practice. I believe that this review is timely and relevant, given growing research interest in this area, and the lack of previous reviews summarising the role of schemas in psychosis. It was an interesting learning experience for me that changed the way I see, and understand, the development of psychosis.

Service Improvement Project

During my first placement, I became interested in the effectiveness of new therapeutic approaches for people with severe and complex mental health difficulties. In particular, I became interested in psychological treatment for people with a diagnosis of Borderline Personality Disorder (BPD). Having looked at the National Institute for Health and Care Excellence (NICE) guidelines, I was struck that despite an increasing body of research evaluating psychological treatment for patients with BPD, the evidence for the effectiveness of different therapeutic models for this population is inconclusive. The service I was based in for my adult mental health placement was struggling with an increased demand for treatment for people with complex mental health problems and symptoms of BPD. Consequently, the service providers proposed setting up a pilot STEPPS group that would constitute an additional treatment choice for people with BPD. When I researched the literature in this field I found a surprising paucity of studies examining effectiveness of the STEPPS programme within a UK secondary care service. This presented an interesting opportunity to evaluate the outcomes of a pilot implementation of the STEPPS programme offered within our service, and contribute to the evidence base for this treatment. In subsequent consultation within the psychology team in that service, we focused on establishing the most appropriate set up of the group, and outcomes measures that would be used to evaluate outcomes of this programme. It was agreed that I would evaluate data from the STEPPS programme to offer recommendations for service improvement, with the aims of improving therapy offered to people with BPD. The paper included in this portfolio presents the evaluation of this project, and a summary of the main findings and recommendation for clinical practice and research.

Main Research Project

Given that my literature review and service improvement projects had focused on complex adult mental health, I felt that it was important to use my main research project as an opportunity to learn about something related to clinical health psychology. In particular, prior to my training I had developed an interest in psycho-oncology, and I was keen to create more learning opportunities in order to further develop my knowledge in this field. Following initial meetings with Dr Jo Daniels and Professor Paul Salkovskis, I began to shape my ideas regarding what would be the most helpful topic to research. Initially, I was interested in examining the effects of rumination and worry on psychological well-being and quality of life amongst cancer patients. This was inspired by emerging research on the usefulness of rumination-focused therapy for depression, and its potential use in clinical health settings. However, after reviewing the literature, I realised that there was a lot of

research that has already been done on rumination and worry in the context of cancer. Over time, having done more reading into this field, I came across emerging research area related to fear of cancer recurrence. I was interested in the clinical implications of that research, and the ways in which fear of cancer recurrence could be best addressed in therapy. This enabled me to narrow down my research idea further: with a specific focus on worries about cancer recurrence and associated distress. Following a number of meetings with my field supervisor Dr Andrew Medley and Professor Paul Salkovskis, we wondered whether exploring the role of health anxiety could be proved fruitful in this area. We also wondered about the influence of additional psychological factors such as self-compassion and mental defeat on the experience of fear of recurrence and psychological distress. This research has proved extremely rewarding, and was in keeping with my interests in clinical health psychology, and improved my understanding of psychological models and their application to clinical practice more generally.

Case Studies

The case studies included in this portfolio demonstrate theory-practice links. They also aim to illustrate that our therapeutic work in clinical psychology is underpinned by our ability to apply psychological models and theories, a reflective formulation driven way. In most of my case studies I followed the same structure linking relevant background literature with a case study description, and a summary of assessment, formulation and intervention. This process helped me clarify my hypothesis related to the specific case, and decide how to best intervene. On all my placements I tried to ensure that I had used enough outcome measures to enable me to write any case up as a case study. This was a helpful habit to develop during training. I found the process of writing up case studies extremely useful and central to my clinical training, and reflection on my own practice. In particular, it illustrated to me the importance of evidence-based practice, inclusion of outcome measures, and evaluation of treatment outcomes.

The reports presented in my case study portfolio cover a range of clients, contexts and evidence-based interventions. They also present some limits and challenges, especially due to the opportunities offered through individual placements. I found feedback on individual case studies from clinical tutors and placement supervisors extremely helpful in terms of learning and reflecting on a range of alternative formulations, treatment models and research issues. Furthermore, the case studies enabled me to reflect on therapy processes and the way in which systemic factors, ethical and professional issues interact and impact on our work and outcomes of therapy. The collection of case studies therefore represents

integration of theoretical knowledge with clinical practice, and my development as a clinician, and future clinical psychologist.

Involvement of service users

In recent years various research charities and organisations have emphasised the importance of service user involvement in clinical research. I was fortunate to be able to consult with some service user in my main research project. However, unfortunately I was unable to do so in my other two pieces of research. This was disappointing, because I am a strong believer that service users have the experience and skills to contribute to the development of research ideas and design. If the needs and views of the service users are included in the research process, it is more likely to produce clinically relevant findings.

The main service user involvement in my research project included contribution that came from a lady who agreed to pilot our questionnaires and information sheet about the study. This enabled us to make specific adaptations to our inclusion criteria (e.g. upper age limit), and ensured that the selection of measures and design of the questionnaire pack were appropriate and ‘user friendly’. Furthermore, many cancer survivors’ who contacted me about the study expressed their support for our research. Some included cards or notes in their questionnaire packs commenting on the usefulness of the research, or specific aspects of the questionnaire, or shared their personal cancer journey. This was very moving and inspiring. I felt a strong sense of support for the study from participants, in particular people from Macmillan Cancer Voices websites, which motivated me to work harder on this research. I also aim to include service users in dissemination of research findings in the form of a newsletter or email for research participants informing them of the latest results of my project. The inclusion of service users in these types of dissemination however requires careful planning to ensure that information is presented in an easily accessible and relevant form.

I was very keen to involve service users in my other projects; however, none of the services I worked with had an active service user involvement team. This created a practical challenge in terms of seeking to involve users in different stages of research. Although I believe that there is scope for service user involvement in all-clinical research, this was certainly more difficult for specific projects, such as my literature review.

Ethical approval

- *Main research project*

I sought ethical approval for my main research project through the Integrated Research Application System (IRAS). As I had no previous experience seeking independently IRAS approval, I found this process was quite complex and time-consuming. However, help from other trainees going through the same process was invaluable.

I also sought Research and Development (R&D) approval from three different NHS trusts involved in our data collection. This process was much more straightforward compared to the IRAS application, with the exception of one trust that took a long time to approve the study. This was due to problems with their internal system for processing applications. In hindsight, in order to avoid such problems it would have been helpful to clarify research project proposals earlier on. This would have enabled me to seek ethical approval from IRAS earlier on, which would have then given me more time to obtain relevant R&D approval. In addition, I sought ethical approval from the University of Bath. This was a relatively straightforward process. My application form was processed in a timely fashion and meant that I could start data collection, and analysis as soon as the university ethics approval has been confirmed.

- *Service improvement project*

In terms of service improvement project, I sought advice from the local NHS R&D department regarding the level of ethical permission that was required for project. Following a telephone consultation with an R&D advisor, it was agreed that the project constituted an audit/ evaluation, as it did not involve any contact with service-users or new data collection apart from the one that was collected as part of the routine treatment. As such, ethical approval from the NHS ethics or R&D was not required for this project. Since this project aimed to evaluate treatment as usual that was already finished, my supervisors and I did not envisage any psychological or physical harm would occur as a result of the evaluation process and data analysis. However, I did obtain ethical approval from the University of Bath, as this project constituted part of my research portfolio.

Recruitment and data collection

- *Service Improvement Project*

Following ethical approval from the University Ethics Committee, data analysis was relatively straightforward and involved the review of outcomes measures and satisfaction feedback collected during the study. The main difficulties in this process included analysis

and presentation of quantitative results, and how to combine and interpret the contrasting results from the qualitative and quantitative analysis. With the support and guidance from the supervisors, we have agreed on the most suitable analysis and we discussed what might be the reasons for contradicting findings from the quantitative and qualitative analysis. Overall, this process has helped me appreciate the value, as well as challenges, related to mixed methods studies. It was great to see how mixed methods design provide opportunities for the integration of different theoretical perspectives, and how integrating or combining these methods can be applied to draw on the strengths of each.

- *Main research project*

Recruitment for my main research project took place across three sites in Bristol, Bath and Swindon. I met with all three of the teams that agreed to help with the research project. The teams were involved in active recruitment or advertisement of the study, and included nurses, doctors, and local psychologists who also acted as research supervisors and collaborators. Help and support from my supervisor Dr Andrew Medley was invaluable and instrumental in liaising with the teams and getting them on board with our research.

Moreover, following advice from Dr Anna Lagerdahl, we added another recruitment site, namely the Macmillan Cancer Voices website. This helped us to maximise the number of people who took part in the study. Cancer voices are people from across the UK who have been affected by cancer in some way. They share their experiences online and help shape research, and other projects, aimed at improving cancer care. I was overwhelmed with the positive response from breast cancer survivors who contacted us through this website. As I already mentioned some of them shared comments on the study and the usefulness of research into fear of cancer recurrence. This was a highly emotional and moving experience. I felt privileged to be part of a research study that aims to raise awareness of psychological distress in cancer survivors, and promote psychological support for people affected by cancer.

Dissemination of research knowledge

Over the summer period I am planning to work on my research publications. In particular, I am aiming to submit my main research project in the *Journal of Psycho-Oncology* and my Literature review in *Psychosis: Psychological, Social and Integrative Approaches*. I hope to prepare and submit for publication some of my case study reports that received particularly positive feedback from course tutors and placement supervisors.

My clinical and research experiences prior and during training confirmed how important it is for me to be guided in my clinical work by evidence based practice, and also to

contribute to it. I believe that effective dissemination can support health care professionals to share information about clinical developments, and help services and individual practitioners implement innovative approaches.

Future involvement in research and service development

During my training, I have developed a strong foundation of post-graduate research, and further increased my interest in service development projects. Although I understand that many psychology jobs do not include time for research, I am planning to maintain research activity and involvement in various service improvement projects throughout my career in Clinical Psychology. In particular, I have already looked for opportunities to get involved in training events, organised by the British Psychological Society and Division of Clinical Psychology, aimed to promote research involvement for clinical psychologists early on in their career. I would also like to find ways of collaborating and contributing to other research projects including those in local doctorate training courses in Clinical Psychology.

Implications for career and future practice

Having enjoyed most of my clinical placements, I am keen to pursue a very wide range of jobs. Despite my specific interests in clinical health psychology and complex adult mental health, I would be keen to pursue a range of different jobs in areas of child and adolescent mental health and older adults services. The breadth of my research and professional portfolio supports this, as the differing topics will be applicable to a variety of fields. I also feel that the variety of research projects I have carried out during my training puts me in a good position to be able to contribute to research, and service development post-qualification.

The art and science of clinical knowledge

I was attracted to the Bath course as it encourages the development of specialist knowledge in psychological theory, and evidence based treatment, and shows how it can be applied to practice through paying close attention to the core values of Clinical Psychology. In particular, during my training I was inspired to learn from many experts in clinical psychology, and great clinicians working in the NHS, who illustrated to me how to skillfully integrate the ‘clinical science’ of psychology, with ‘clinical art’ that emphasizes reflective practice, person-centered, and culturally sensitive approaches. I am inspired to continue to draw on the art and science of clinical psychology in my future clinical and research work.

Acknowledgements

I would like to express my special appreciation and thanks to my supervisor Dr Andrew Medley, who have supported and guided me through this research. His enthusiasm, kindness and insight into research and clinical implications have been priceless. I would also like to thank Professor Paul Salkovskis for his scientific advice and knowledge, and many insightful discussions and suggestions. I would also like to thank Lorna Hogg, for her help and supervision with my literature review project and giving me support and encouragement to chose a topic that was interesting to me. I would like to thank Josie Millar for her support and kind, and gentle attitude and helping me with my service improvement project. I would especially like to thank all field supervisors, doctors and nurses for their support and help with data collection and helpful suggestions for my thesis.

A special thanks to my family, my mother Janka Grozdziej and father Adam Grozdziej, my sisters Renata and Agnieszka, for their love and support throughout my studies, for believing in me and supporting me at the times when I most doubted myself, and encouraging me to strive and achieve my goals. I also thank my friends for providing support and friendship that I needed.

Last but not least, I would like to express appreciation to my dear boyfriend Tom Foley for his love, support, and understanding throughout my training. For instilling hope and confidence in me, and making my life so beautiful.

Appendices

(A) Appendices for Literature Review

Appendix A1. Instructions for authors

Instructions for authors and brief reasons for choosing this journal

Psychosis: Psychological, Social and Integrative Approaches is a new journal that accepts original articles related to research on the psychological treatments of psychosis, and the psycho-social causes of psychosis. The journal publishes papers on both quantitative and qualitative research, as well as papers focusing on conceptual and ethical issues. This journal was chosen as its aims and scope relates directly to the topic of the critical review of the literature.

General guidelines for manuscript preparation

- Manuscripts should be consistent with the Aims and Scope of the journal.
- Research articles and reviews should not exceed 5,000 words.
- Abstract of 200 words is required for all manuscripts submitted.
- Each paper should have up to five keywords
- Section headings should be concise.
- A subsection subtitled Clinical Implications is required in Discussion.
- Tables should be numbered consecutively with Arabic numbers in order of appearance in the text. Type each table double-spaced on a separate page, with a short descriptive title typed directly above and with essential footnotes below.
- The style and format of the typescripts should conform to the APA referencing style.

(B) Appendices for Service Improvement Project

Appendix B1. Instructions for authors

Instructions for authors and brief reasons for choosing this journal

Comprehensive Psychiatry provides a forum for clinicians and investigators of markedly divergent concepts, methods and orientations. Clear, concise reports cover developments in clinical and basic investigations as well as new diagnostic and therapeutic practices.

General guidelines for manuscript preparation

- Manuscripts should be consistent with the Aims and Scope of the journal.
- Each paper should have up to six keywords
- The text should be in single-column format with the layout of the text as simple as possible.
- Article should be divided into clearly defined and numbered sections.
- Any subsection may be given a brief heading. Each heading should appear on its own separate line.
- A structured abstract, by means of appropriate headings, should provide the context or background for the research and should state its purpose, basic procedures (selection of study subjects or laboratory animals, observational and analytical methods), main findings (giving specific effect sizes and their statistical significance, if possible), and principal conclusions. It should emphasize new and important aspects of the study or observations.
- *Highlights* are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. 'Highlights' should include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).
- *Introduction* - State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.
- *Material and methods* - Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.
- *Results* Results should be clear and concise.
- *Discussion* - This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate.

Avoid extensive citations and discussion of published literature.

- *Conclusions* - The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.
- *Reference style* - Indicate references by superscript numbers in the text. The actual authors can be referred to, but the reference number(s) must always be given. *List:* Number the references in the list in the order in which they appear in the text.
- *Appendices* - If there is more than one appendix, they should be identified as A, B, etc.

Appendix B2. Measures used

BEST® (Borderline Evaluation of Severity over Time)

For the first 12 items, the highest rating (5) means that the item caused extreme distress, severe difficulties with relationships, and/or kept you from getting things done. The lowest rating (1) means it caused little or no problems. Rate items 13-15 (positive behaviours) according to frequency.

| Circle the time period you have been asked to rate: | Last 7 Days | Last 30 Days | Other |
|---|-------------|--------------|-----------|
| Circle the number that indicates how much the item has caused distress, relationship problems, or difficulty with getting things done. | | | |
| A. Thoughts and Feelings [] | | | |
| 1. Worrying that someone important in your life is tired of you or is planning to leave you | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 2. Major shifts in your opinions about others such as switching from believing someone is a loyal friend or partner to believing that person is untrustworthy and hurtful | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 3. Extreme changes in how you see yourself. Shifting from feeling confident about who you are to feeling like you are evil, or that you don't even exist | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 4. Severe mood swings several times a day. Minor events cause major shifts in mood | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 5. Feeling paranoid or like you are losing touch with reality | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 6. Feeling angry | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 7. Feelings of emptiness | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 8. Feeling suicidal | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |

To the clinician: the total for each section (A, B, and C) should be recorded in the brackets following the section titles. At the top of the page record the total composite score (15 + A + B + C)

STEPS Manual.UK L1.2

Name: _____ ID# _____

Total Score: _____ Date: _____

B. Behaviours (Negative) []

| None/slight | Mild | Moderate | Severe | Extreme |
|---|-----------|-----------|-----------|-----------|
| 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 9. Going to extremes to try to keep someone from leaving you | | | | |
| 10. Purposely doing something to injure yourself or making a suicide attempt | | | | |
| 11. Problems with impulsive behaviour (not including suicide attempts or injuring yourself on purpose) Examples are: overspending, risky sexual behaviour, substance abuse, reckless driving, binge eating, other _____ (circle those that apply) | | | | |
| 12. Temper outbursts or problems with anger leading to relationship problems, physical fights, or destruction of property | | | | |

Circle the number that indicates how often you used the following positive behaviours

C. Behaviours (Positive) []

| Almost always | Most of the time | Half of the time | Sometimes | Almost never |
|--|------------------|------------------|-----------|--------------|
| 5 4 3 2 1 | 5 4 3 2 1 | 5 4 3 2 1 | 5 4 3 2 1 | 5 4 3 2 1 |
| 13. Choosing to use a positive activity in circumstances where you felt tempted to do something destructive or self-defeating | | | | |
| 14. Noticing ahead of time that something could cause you emotional difficulties and taking reasonable steps to avoid/prevent the problem | | | | |
| 15. Following through with therapy plans to which you agreed (e.g., talk therapy, "homework" assignments, coming to appointments, medications, etc.) | | | | |

© 1997 Bruce Pfohl, MD & Nancee Blum, MSW
Excerpted from STEPS™, Group Treatment Programme for Borderline Personality Disorder
www.stepsforbpd.com

EVALUATION OF THE SERVICES

We would be very grateful if you could answer some questions about the services you have received as a part of your treatment. This will help us to improve our work and the services we offer. Please give us your honest opinions, whether they are positive or negative, as these will help us when evaluating and improving this service. Your feedback will be fed back to the team anonymously and in a sensitive and constructive way.

Please feel free to write any comments you may have or ideas for how things could be improved under any of the sections. You can use additional sheets if you would like to. For the questions which involve circling a number please could you answer them by circling the number that best represents your experience of the services.

1= Strongly disagree 2= Disagree 3= Neither agree nor disagree 4= Agree 5= Strongly agree

Thank you very much, we appreciate your help.

1) OVERALL SATISFACTION

| | Strongly Disagree | Disagree | Uncertain | Agree | Strongly Agree |
|---|----------------------|----------|-----------|-------|-------------------|
| Overall, I was satisfied with my experience of this clinic. | 1 | 2 | 3 | 4 | 5 |

2) INFORMATION/CONTACT WITH THE CLINIC

Information communicated to everyone referred to this service should help people know what to expect when they go to the clinic:

| | Strongly Disagree | Disagree | Uncertain | Agree | Strongly Agree |
|--|----------------------|----------|-----------|-------|-------------------|
| I received enough information on what to expect before I was first seen. | 1 | 2 | 3 | 4 | 5 |
| I am satisfied with how and when I received information (e.g. appointment letters, information sheets, phone calls). | 1 | 2 | 3 | 4 | 5 |
| The secretaries and the admin staff were helpful. | 1 | 2 | 3 | 4 | 5 |
| Written communication from the service was clear and effective. | 1 | 2 | 3 | 4 | 5 |

What would have improved your satisfaction with the information you received from the Service?

3) WAITING TIME

There can be a long wait to be seen at this service

How long did you wait for your assessment?

How long did you wait for your 1st treatment session?

| | Strongly Disagree | Disagree | Uncertain | Agree | Strongly Agree |
|---|----------------------|----------|-----------|-------|-------------------|
| I was satisfied with the waiting time for assessment | 1 | 2 | 3 | 4 | 5 |
| I was satisfied with the waiting time for treatment | 1 | 2 | 3 | 4 | 5 |
| I was satisfied with the information I received about waiting times | 1 | 2 | 3 | 4 | 5 |

What could have improved your satisfaction with and understanding of the waiting times?

4) QUESTIONNAIRES

People are asked to fill in a number of questionnaires at various stages in treatment; how did you find this?

| | Strongly Disagree | Disagree | Uncertain | Agree | Strongly Agree |
|---|----------------------|----------|-----------|-------|-------------------|
| The reasons I was given for completing the questionnaires were satisfactory | 1 | 2 | 3 | 4 | 5 |

5) YOUR TREATMENT

This service aims to provide the best possible therapy for each individual.

| | Strongly Disagree | Disagree | Uncertain | Agree | Strongly Agree |
|---|----------------------|----------|-----------|-------|-------------------|
| I felt involved in choices about how my treatment was done | 1 | 2 | 3 | 4 | 5 |
| The help provided at the clinic allowed me to resolve my main problem | 1 | 2 | 3 | 4 | 5 |
| The help provided at the clinic allowed me to resolve other problems in my life | 1 | 2 | 3 | 4 | 5 |
| Some of the things the therapist did were unhelpful | 1 | 2 | 3 | 4 | 5 |
| I felt I was listened to by my therapist | 1 | 2 | 3 | 4 | 5 |
| I felt treated with respect by my therapist | 1 | 2 | 3 | 4 | 5 |

Are there ways in which therapy could have been more helpful?

ANY OTHER COMMENTS/SUGGESTIONS

If you would like to make any further comments on any of your answers above or any further aspect of the service you have received, we would really welcome them. Similarly, if you have any suggestions or ideas about how we could improve the service they would be really helpful. You can use the space below and any extra sheets you might need.

STEPPS Treatment Evaluation Survey

Please help us improve our service by answering some questions about the treatment you have received in the **Systems Training for Emotional Predictability and Problem Solving (STEPPS)** group treatment. We are interested in your honest opinions, whether they are positive or negative. Please answer all of the questions. We also welcome your comments and suggestions. Thank you very much, we appreciate your help. Please circle your answer.

1. "I attended more than half of the sessions"

| | | | | |
|-------------------|----------|---------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |

2. "I was given a very clear explanation of what BPD means"

| | | | | |
|-------------------|----------|---------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |

3. "I did not find the manual helpful"

| | | | | |
|-------------------|----------|---------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |

4. "The sessions were very helpful, and taught me how to handle difficulties better"

| | | | | |
|-------------------|----------|---------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |

5. "The skills I learned are highly effective"

| | | | | |
|-------------------|----------|---------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |

6. "Skill cards helped me to explain my illness to others"

| | | | | |
|-------------------|----------|---------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |

7. "After STEPPS, people say I have fewer problems"

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

| | | | | |
|-------------------|----------|---------|-------|----------------|
| Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|-------------------|----------|---------|-------|----------------|

8. “After STEPPS, I have been much less likely to harm myself”

| | | | | |
|-------------------|----------|---------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |

9. “Amount of materials”

| | | | | |
|------------|--------|--------|------|----------|
| 1 | 2 | 3 | 4 | 5 |
| Too little | Little | Enough | Much | Too much |

10. “Time to discuss my intense emotions”

| | | | | |
|------------|--------|--------|------|----------|
| 1 | 2 | 3 | 4 | 5 |
| Too little | Little | Enough | Much | Too much |

11. “Length of sessions”

| | | | | |
|------------|--------|--------|------|----------|
| 1 | 2 | 3 | 4 | 5 |
| Too little | Little | Enough | Much | Too much |

12. “Number of sessions”

| | | | | |
|------------|--------|--------|------|----------|
| 1 | 2 | 3 | 4 | 5 |
| Too little | Little | Enough | Much | Too much |

13. “Time provided to learn new skills”

| | | | | |
|------------|--------|--------|------|----------|
| 1 | 2 | 3 | 4 | 5 |
| Too little | Little | Enough | Much | Too much |

PLEASE WRITE ANY OTHER COMMENTS

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

CLINICAL OUTCOMES in ROUTINE EVALUATION

OUTCOME MEASURE

Site ID

letters only numbers only

Client ID

Therapist ID

Sub codes / /

Date form given /

Age

Male ☐ Female ☐

Stage Completed

S Screening ☐ Stage

R Referral ☐

A Assessment ☐

F First Therapy Session ☐

P Pre-therapy (unspecified) ☐

D During Therapy ☐

L Last therapy session ☐

X Follow up 1 ☐

Y Follow up 2 ☐

Episode

IMPORTANT - PLEASE READ THIS FIRST

This form has 34 statements about how you have been OVER THE LAST WEEK.
Please read each statement and think how often you felt that way last week.
Then tick the box which is closest to this.
Please use a dark pen (not pencil) and tick clearly within the boxes.

Over the last week

| | Not at all | Only Occasionally | Sometimes | Often | Most or all the time | OFFICE USE ONLY |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 1 I have felt terribly alone and isolated | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> F |
| 2 I have felt tense, anxious or nervous | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 3 I have felt I have someone to turn to for support when needed | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> F |
| 4 I have felt O.K. about myself | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> W |
| 5 I have felt totally lacking in energy and enthusiasm | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 6 I have been physically violent to others | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> R |
| 7 I have felt able to cope when things go wrong | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> F |
| 8 I have been troubled by aches, pains or other physical problems | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 9 I have thought of hurting myself | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> R |
| 10 Talking to people has felt too much for me | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> F |
| 11 Tension and anxiety have prevented me doing important things | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 12 I have been happy with the things I have done. | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> F |
| 13 I have been disturbed by unwanted thoughts and feelings | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 14 I have felt like crying | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> W |

Please turn over

| Over the last week | | Not at all | Only Occasionally | Sometimes | Often | Most or all the time | OFFICE USE ONLY |
|---|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 15 | I have felt panic or terror | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 16 | I made plans to end my life | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> R |
| 17 | I have felt overwhelmed by my problems | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> W |
| 18 | I have had difficulty getting to sleep or staying asleep | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 19 | I have felt warmth or affection for someone | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> F |
| 20 | My problems have been impossible to put to one side | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 21 | I have been able to do most things I needed to | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> F |
| 22 | I have threatened or intimidated another person | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> R |
| 23 | I have felt despairing or hopeless | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 24 | I have thought it would be better if I were dead | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> R |
| 25 | I have felt criticised by other people | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> F |
| 26 | I have thought I have no friends | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> F |
| 27 | I have felt unhappy | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 28 | Unwanted images or memories have been distressing me | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 29 | I have been irritable when with other people | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> F |
| 30 | I have thought I am to blame for my problems and difficulties | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> P |
| 31 | I have felt optimistic about my future | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> W |
| 32 | I have achieved the things I wanted to | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> F |
| 33 | I have felt humiliated or shamed by other people | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> F |
| 34 | I have hurt myself physically or taken dangerous risks with my health | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> R |
| THANK YOU FOR YOUR TIME IN COMPLETING THIS QUESTIONNAIRE | | | | | | | |
| Total Scores | | <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> | → <input type="text"/> | → <input type="text"/> |
| Mean Scores | | <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| (Total score for each dimension divided by number of items completed in that dimension) | | (W) | (P) | (F) | (R) | All items | All minus R |

Appendix B3. Information relevant to ethical review

The Service Improvement Project received approval from The University of Bath Research Ethics Committee (reference number 13-161). In the absence of a formal letter, please contact psychology-ethics@bath.ac.uk for further information.

(C) Appendices for Main research project

Appendix C1. Instructions for authors

- Manuscript Submission - All papers must be submitted via the online system. *Psycho-Oncology* operates an online submission and peer review system that allows authors to submit articles online and track their progress via a web interface.
- Copyright and Permissions - If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.
- Submission of a manuscript will be held to imply that it contains original unpublished work and is not being submitted for publication elsewhere at the same time. Submitted material will not be returned to the author, unless specifically requested.
- Manuscript style. The language of the journal is English. 12-point type in one of the standard fonts: Times, Helvetica, or Courier is preferred. It is not necessary to double-line space your manuscript. There should be a separate title page with full information and another page for an abstract, prior to the Introduction. Tables must be on separate pages after the reference list, and not be incorporated into the main text. Figures should be uploaded as separate figure files.
- During the submission process you must enter the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs. Include the name(s) of any sponsor(s) of the research contained in the paper, along with grant number(s).
- Enter an abstract of up to 250 words for all articles. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable

without reference to the rest of the paper. It should contain no citation to other published work. You must submit your abstract according to these headings: objective; methods; results; conclusions.

- Include up to six keywords which must contain the words cancer and oncology that describe your paper for indexing purposes.
- Research Articles should not exceed 4000 words (including no more than four figures and/or tables) plus up to 40 references. Review papers of up to 6000 words will be considered, with 80 references - authors should contact the Editors for advice. All papers should use the following headings: Background, Methods (including statistical methods), Results, Conclusions. Word counts should include the title page, abstract, main manuscript, tables and figures, but exclude the references.
- Qualitative manuscript submissions should usually be based on a minimum of 20 respondents. Authors may contact the Editors if they require further details.
- Reference style. References should be cited in the text by number within square brackets and listed at the end of the paper in the order in which they appear in the text. All references must be complete and accurate. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. Where possible the DOI for the reference should be included at the end of the reference. Online citations should include date of access. References should be listed in the following style: Decker, CL. Social support and adolescent cancer survivors: A review of the literature. *Psycho-Oncology* 2007; 16 : 1-11. Peterson AC, Leffert N. What is special about adolescence? In *Psychosocial Disturbances in Young People: Challenges for Prevention*, Rutter M (ed.). Cambridge University Press: Cambridge, 1997;3-36.
- Tables should be part of the the main document and should be placed after the references. If the table is created in excel the file should be uploaded separately.
- Ethics. Authors of research papers should provide information about funding, a Conflict of Interest statement, details of ethical committee review, and (if the paper is a clinical trial) details of trial registration. All of these declarations should be in the research paper itself, not a covering letter. If authors include named individuals in the Acknowledgements they must confirm that they have approval from those individuals in their covering letter
- Post Acceptance. Further Information. For accepted manuscripts the publisher will supply proofs to the submitting author prior to publication. This stage is to be used

only to correct errors that may have been introduced during the production process. Prompt return of the corrected proofs, preferably within two days of receipt, will minimise the risk of the paper being held over to a later issue. Free access to the final PDF offprint of your article will be available via Author Services only.

Appendix C2. Measures used

Participant ID no. _____

Department of
Psychology



UNIVERSITY OF
BATH

Dear Participant,

Thank you for kindly agreeing to take part in this study.

Worry and anxiety after treatment for cancer is very common and entirely normal and understandable. These worries can include fears about the risk of cancer returning in the future, which can become quite troublesome and disruptive for some people.

Your answers to this questionnaire will help us to better understand factors related to intrusive or persistent fear about cancer recurrence. These new insights should then help us to design and provide more effective and timely psychological and emotional support, as an integral part of cancer care services in this region and beyond.

The questionnaire will take about 15 to 20 minutes to complete. If you have any questions regarding this study, then please contact us using details provided in the information sheet. We very much appreciate your help in taking time to complete this questionnaire.

With our best wishes,

The Research Team

Health Anxiety

This questionnaire is asking about a *general tendency* to worry about one's health, so the questions do not necessarily relate to worries about cancer.

Each question consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings, **over the past three months**. Identify the statement by **circling the letter** next to it, i.e. if you think that statement **a.** is correct, circle statement **a.** It may be that more than one statement applies, in which case, please circle any that are applicable.

- 1 a. I do not worry about my health
 b. I occasionally worry about my health
 c. I spend much of my time worrying about my health
 d. I spend most of my time worrying about my health

- 2 a. I notice aches/pains less than most other people (of my age)
 b. I notice aches/pains as much as most other people (of my age)
 c. I notice aches/pains more than most other people (of my age)
 d. I am aware of aches/pains in my body all the time

- 3 a. As a rule I am not aware of bodily sensations or changes
 b. Sometimes I am aware of bodily sensations or changes
 c. I am often aware of bodily sensations or changes
 d. I am constantly aware of bodily sensations or changes

- 4 a. Resisting thoughts of illness is never a problem
 b. Most of the time I can resist thoughts of illness
 c. I try to resist thoughts of illness but am often unable to do so
 d. Thoughts of illness are so strong that I no longer even try to resist them

- 5 a. As a rule I am not afraid that I have a serious illness
 b. I am sometimes afraid that I have a serious illness
 c. I am often afraid that I have a serious illness
 d. I am always afraid that I have a serious illness

- 6 a. I do not have images (mental pictures) of myself being ill
 b. I occasionally have images of myself being ill
 c. I frequently have images of myself being ill
 d. I constantly have images of myself being ill

- 7 a. I do not have any difficulty taking my mind off thoughts about my health
 b. I sometimes have difficulty taking my mind off thoughts about my health
 c. I often have difficulty in taking my mind off thoughts about my health
 d. Nothing can take my mind off thoughts about my health

- 8 a. I am lastingly relieved if my doctor tells me there is nothing wrong
b. I am initially relieved but the worries sometimes return later
c. I am initially relieved but the worries always return later
d. I am not relieved if my doctor tells me there is nothing wrong
- 9 a. If I hear about an illness I never think I have it myself
b. If I hear about an illness I sometimes think I have it myself
c. If I hear about an illness I often think I have it myself
d. If I hear about an illness I always think I have it myself
- 10 a. If I have a bodily sensation or change I rarely wonder what it means
b. If I have a bodily sensation or change I often wonder what it means
c. If I have a bodily sensation or change I always wonder what it means
d. If I have a bodily sensation or change I must know what it means
- 11 a. I usually feel at very low risk for developing a serious illness
b. I usually feel at fairly low risk for developing a serious illness
c. I usually feel at moderate risk for developing a serious illness
d. I usually feel at high risk for developing a serious illness
- 12 a. I never think I have a serious illness
b. I sometimes think I have a serious illness
c. I often think I have a serious illness
d. I usually think that I am seriously ill
- 13 a. If I notice an unexplained bodily sensation I don't find it difficult to think about other things
b. If I notice an unexplained bodily sensation I sometimes find it difficult to think about other things
c. If I notice an unexplained bodily sensation I often find it difficult to think about other things
d. If I notice an unexplained bodily sensation I always find it difficult to think about other things
- 14 a. My family/friends would say I do not worry enough about my health
b. My family/friends would say I have a normal attitude to my health
c. My family/friends would say I worry too much about my health
d. My family/friends would say I am a hypochondriac

Emotional Reactions to Difficult Circumstances

This questionnaire is about how you feel **currently in relation to your experience of cancer**. In the following, you will find a number of statements that describe thoughts and feelings that people sometimes experience in the face of serious illness or symptoms. Please rate the extent to which these statements apply to your experience **at present** by circling the appropriate number. There are no right or wrong answers to these questions. Please remember that this questionnaire is about how you feel and think **at present**.

| Because of cancer... | | Not at all / Never | Very little | Moderately | Strongly | Very strongly |
|----------------------|---|-----------------------|-------------|------------|----------|------------------|
| 1 | I feel defeated by life..... | 0 | 1 | 2 | 3 | 4 |
| 2 | I feel that I have lost my standing in the world..... | 0 | 1 | 2 | 3 | 4 |
| 3 | I feel that life has treated me like a punchbag..... | 0 | 1 | 2 | 3 | 4 |
| 4 | I feel powerless..... | 0 | 1 | 2 | 3 | 4 |
| 5 | I feel that my confidence has been knocked out of me..... | 0 | 1 | 2 | 3 | 4 |
| 6 | I don't feel able to deal with things that life throws at me..... | 0 | 1 | 2 | 3 | 4 |
| 7 | I feel that I have sunk to the bottom of the ladder..... | 0 | 1 | 2 | 3 | 4 |
| 8 | I feel completely knocked out of action..... | 0 | 1 | 2 | 3 | 4 |
| 9 | I feel that I am one of life's losers..... | 0 | 1 | 2 | 3 | 4 |
| 10 | I feel that I have given up..... | 0 | 1 | 2 | 3 | 4 |
| 11 | I feel down and out..... | 0 | 1 | 2 | 3 | 4 |
| 12 | I feel I have lost important battles in life..... | 0 | 1 | 2 | 3 | 4 |
| 13 | I feel that there is no fight left in me.. | 0 | 1 | 2 | 3 | 4 |
| 14 | I feel I am losing my will power..... | 0 | 1 | 2 | 3 | 4 |
| 15 | I don't care what happens to me anymore..... | 0 | 1 | 2 | 3 | 4 |
| 16 | I feel defeated..... | 0 | 1 | 2 | 3 | 4 |
| 17 | I feel less like a human being..... | 0 | 1 | 2 | 3 | 4 |
| 18 | In my mind, I give up..... | 0 | 1 | 2 | 3 | 4 |
| 19 | I feel destroyed as a person..... | 0 | 1 | 2 | 3 | 4 |
| 20 | I feel like I want to die..... | 0 | 1 | 2 | 3 | 4 |
| 21 | I feel like I am losing my inner resistance..... | 0 | 1 | 2 | 3 | 4 |
| 22 | I feel like an object..... | 0 | 1 | 2 | 3 | 4 |
| 23 | I feel completely at the mercy of what is happening to me..... | 0 | 1 | 2 | 3 | 4 |
| 24 | I feel humiliated and that I am losing my sense of inner dignity..... | 0 | 1 | 2 | 3 | 4 |

How I typically act towards myself in difficult times...

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never

1

2

3

4

Almost always

5

_____ When I fail at something important to me I become consumed by feelings of inadequacy.

_____ I try to be understanding and patient towards those aspects of my personality I don't like.

_____ When something painful happens I try to take a balanced view of the situation.

_____ When I'm feeling down, I tend to feel like most other people are probably happier than I am.

_____ I try to see my failings as part of the human condition.

_____ When I'm going through a very hard time, I give myself the caring and tenderness I need.

_____ When something upsets me I try to keep my emotions in balance.

_____ When I fail at something that's important to me, I tend to feel alone in my failure

_____ When I'm feeling down I tend to obsess and fixate on everything that's wrong.

_____ When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.

_____ I'm disapproving and judgmental about my own flaws and inadequacies.

_____ I'm intolerant and impatient towards those aspects of my personality I don't like.

Worry about cancer

Most people who have been diagnosed with cancer are worried, to varying degrees, that there might be a recurrence of the cancer. **By recurrence, we mean the possibility that the cancer could return or progress in the same place or in another part of the body.** This questionnaire aims to better understand the experience of worries about cancer recurrence. Please read each statement and indicate to what degree it applied to you **during the past month** by **circling the appropriate number.**

1. I am worried or anxious about the possibility of cancer recurrence.

| | | | | |
|---------------------|-------------------|-------------------|----------------|-----------------------|
| 0 Not at all | 1 A little | 2 Somewhat | 3 A lot | 4 A great deal |
|---------------------|-------------------|-------------------|----------------|-----------------------|

2. I am afraid of cancer recurrence.

| | | | | |
|---------------------|-------------------|-------------------|----------------|-----------------------|
| 0 Not at all | 1 A little | 2 Somewhat | 3 A lot | 4 A great deal |
|---------------------|-------------------|-------------------|----------------|-----------------------|

3. I believe it is normal to be worried or anxious about the possibility of cancer recurrence.

| | | | | |
|---------------------|-------------------|-------------------|----------------|-----------------------|
| 0 Not at all | 1 A little | 2 Somewhat | 3 A lot | 4 A great deal |
|---------------------|-------------------|-------------------|----------------|-----------------------|

4. When I think about the possibility of cancer recurrence, this triggers other unpleasant thought or images (such as death, suffering, the consequences for my family).

| | | | | |
|---------------------|-------------------|-------------------|----------------|-----------------------|
| 0 Not at all | 1 A little | 2 Somewhat | 3 A lot | 4 A great deal |
|---------------------|-------------------|-------------------|----------------|-----------------------|

5. I believe that I am cured and that the cancer will not come back.

| | | | | |
|---------------------|-------------------|-------------------|----------------|-----------------------|
| 0 Not at all | 1 A little | 2 Somewhat | 3 A lot | 4 A great deal |
|---------------------|-------------------|-------------------|----------------|-----------------------|

6. In your opinion, are you at risk of having a cancer recurrence?

| | | | | |
|-----------------------------|---------------------------|---------------------------|------------------------|-------------------------------|
| 0 Not at all at risk | 1 A little at risk | 2 Somewhat at risk | 3 A lot at risk | 4 A great deal at risk |
|-----------------------------|---------------------------|---------------------------|------------------------|-------------------------------|

7. How often do you think about the possibility of cancer recurrence?

| | | | | |
|----------------|------------------------------|-----------------------------|----------------------------|------------------------------|
| 0 Never | 1 A few times a month | 2 A few times a week | 3 A few times a day | 4 Several times a day |
|----------------|------------------------------|-----------------------------|----------------------------|------------------------------|

8. How much time per day do you spend thinking about the possibility of cancer recurrence?

| | | | | |
|---------------------------------|------------------------|------------------------|----------------------|------------------------|
| 0 I don't think about it | 1 A few seconds | 2 A few minutes | 3 A few hours | 4 Several hours |
|---------------------------------|------------------------|------------------------|----------------------|------------------------|

9. How long have you been thinking about the possibility of cancer recurrence?

| | | | | |
|---------------------------------|----------------------|-----------------------|----------------------|------------------------|
| 0 I don't think about it | 1 A few weeks | 2 A few months | 3 A few years | 4 Several years |
|---------------------------------|----------------------|-----------------------|----------------------|------------------------|

PHQ-9 Mood questionnaire

| Over the <i>last 2 weeks</i> , how often have you been bothered by any of the following problems? (Use “✓” to indicate your answer”) | Not at all | Several days | More than half the days | Nearly every day |
|---|---------------|-----------------|----------------------------------|------------------------|
| 1. Little interest or pleasure in doing things. | 0 | 1 | 2 | 3 |
| 2. Feeling down, depressed, or hopeless. | 0 | 1 | 2 | 3 |
| 3. Trouble falling or staying asleep, or sleeping too much. | 0 | 1 | 2 | 3 |
| 4. Feeling tired or having little energy. | 0 | 1 | 2 | 3 |
| 5. Poor appetites or overeating. | 0 | 1 | 2 | 3 |
| 6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down. | 0 | 1 | 2 | 3 |
| 7. Trouble concentrating on things, such as reading the newspaper or watching television. | 0 | 1 | 2 | 3 |
| 8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual. | 0 | 1 | 2 | 3 |
| 9. Thoughts that you would be better off dead, or of hurting yourself. | 0 | 1 | 2 | 3 |

If you checked off *any problems*, how *difficult* have these problems made it for you to do your work,
take care of things at home, or get along with other people?

**Not difficult
at all**
☐

**Somewhat
difficult**
☐

**Very
difficult**
☐

**Extremely
difficult**
☐

GAD-7 Mood questionnaire

| Over the <i>last 2 weeks</i>, how often have you been bothered by the following problems? (Use “✓” to indicate your answer) | Not at all | Several days | More than half the days | Nearly every day |
|--|-----------------------|-------------------------|--|-----------------------------|
| 1. Feeling nervous, anxious or on edge | 0 | 1 | 2 | 3 |
| 2. Not being able to stop or control worrying | 0 | 1 | 2 | 3 |
| 3. Worrying too much about different things | 0 | 1 | 2 | 3 |
| 4. Trouble relaxing | 0 | 1 | 2 | 3 |
| 5. Being so restless that it is hard to sit still | 0 | 1 | 2 | 3 |
| 6. Becoming easily annoyed or irritable | 0 | 1 | 2 | 3 |
| 7. Feeling afraid as if something awful might happen | 0 | 1 | 2 | 3 |

Health-related coping behaviours

This section will help us to understand the types of coping strategies that you employ in relation to monitoring your health and wellbeing.

1. In the past 12 months, how many times have you visited your GP or Oncologist/Specialist Nurse to discuss potential symptoms of recurrence over and above your routine follow-up appointments?

| | |
|---|--|
| Number of GP visits: (Please specify) | Number of Oncologist or Special Nurse visits: (Please specify) |
|---|--|

2. In the past 12 months, how many times have you visited your GP for any reason?
Please tick the appropriate box below ✓

| | | | | |
|-------------------|----------------------------------|----------------|--------------------|---------------|
| Not at all | Rarely (up to 6 times) | Monthly | Fortnightly | Weekly |
| | | | | |

3. What is the average frequency of your self-examination of your breasts or other parts of the body? Please tick the appropriate box below ✓

| | | | | | |
|-------------------|-----------------------------|----------------|---------------|--------------|------------------------------|
| Not at all | A few times per year | Monthly | Weekly | Daily | Several times per day |
| | | | | | |

4. To what extent do you use Internet searches to seek out information related to your diagnosis of cancer and the risk of recurrence in the future? Please tick the appropriate box below ✓

| | | | | | |
|-------------------|-----------------------------|----------------|---------------|--------------|------------------------------|
| Not at all | A few times per year | Monthly | Weekly | Daily | Several times per day |
| | | | | | |

5. To what extent do you seek verbal reassurance from people around you (e.g. family, friends, other people affected by cancer, or your healthcare team) in relation to your diagnosis of cancer and the risk of recurrence in the future? Please tick the appropriate box below ✓

| | | | | | |
|-------------------|-----------------------------|----------------|---------------|--------------|------------------------------|
| Not at all | A few times per year | Monthly | Weekly | Daily | Several times per day |
| | | | | | |

Demographic and treatment information

Age: _____

Date of diagnosis: _____

Date of completion of chemotherapy or radiotherapy treatment (whichever later): _____

Type of treatment you have received – please tick ✓ all that apply:

| | |
|--------------|--|
| Surgery | |
| Radiotherapy | |
| Chemotherapy | |
| Herceptin | |
| Endocrine | |

Please read the following advice carefully:

If you feel upset or distressed as a result of completing this questionnaire, then please don't hesitate to contact a member of the research team (using the contact details on the Participant Information Sheet) or your Specialist Nurse to talk things through.

If your answers to any of the questions in this form indicate that you are experiencing thoughts about harming yourself, then please consider contacting your GP, Specialist Nurse, or other member of your healthcare team without delay to discuss options for further support. If these answers lead us to feel especially concerned about your wellbeing, then we will discuss this with your Oncology team so that they can make contact with you and your GP to discuss your preferences and needs for additional support.

If you feel the need to speak with somebody urgently, then please consider contacting the Samaritans on **08457 909090**

Thank you so much for your time and taking part in this study.

**With our best wishes,
The Research Team**

DEMOGRAPHIC INFORMATION
Study of health anxiety in cancer recovery
(Ania Grozdziej & Dr Andrew Medley, University of Bath)

Please answer each of the following questions by ticking ☒ the relevant check boxes.

Please then return the form to the University of Bath in the Freepost envelope provided.

Please tick ☒ the relevant check boxes for each of the following questions:

1. What is your ethnic group?

White ☐
Asian ☐
Black (Caribbean, African, Others) ☐
Hispanic/Latino ☐
Mixed Background ☐
Others: _____

2. What is your highest educational qualification?

No formal qualification ☐
Primary ☐
Secondary (e.g. GCSE, O-Levels, GNVQ) ☐
Diploma (or professional qualification) ☐
Degree ☐
Postgraduate ☐
Others: _____

**3. What is your relationship status?
(tick all boxes that apply)**

Single ☐
In a relationship ☐
Cohabiting ☐
Engaged ☐
Married ☐
Separating ☐
Divorced ☐
Widowed ☐
Other: _____

**4. What is your employment situation?
(tick all boxes that apply)**

Paid work ☐
Unpaid work ☐
On sick leave ☐
Unemployed ☐
Student ☐
Other: _____

Thank you very much for taking the time to complete and return this form.

With our best wishes,

The Research Team

Appendix C3 Information sheet

Department of
Psychology



Health anxiety and fear of recurrence in breast cancer survivors

What is the study about?

We are interested in understanding more about the worry and anxiety that people often experience about their health after completing treatment for cancer. We know that fears about cancer returning in the future, or worries about health in general, are common and entirely normal in people who have completed treatment. Sometimes, however, people can experience a quite disruptive and intrusive level of fear and anxiety. So we would like to find out about which factors in particular (e.g. worries about physical symptoms or feeling emotionally 'defeated' by illness) seem to influence overall mood and the intensity of anxiety. This should help us to design more effective psychological therapies to support people in better managing their worries and emotional wellbeing.

Who can take part?

We would like to invite people to take part who are over the age of 18 years and are attending hospital follow-up appointments after completing their primary treatment with curative intent for breast cancer. We are working with the following cancer centres: Royal United Hospital in Bath, Southmead Hospital in Bristol, and Great Western Hospital in Swindon.

What are the benefits?

Although there are no direct or immediate benefits to you from taking part in the study, we hope and anticipate that the findings will help us to better understand the reasons why fears about cancer recurrence seem to be more intense and intrusive for some people after completing treatment. This should then help us to design and provide more effective and timely psychological and emotional support, as an integral part of cancer care services in this region and beyond.

What will I have to do?

We would like to invite you to complete a set of brief questionnaires about different aspects of your wellbeing. The questionnaires should take approximately 20 minutes to complete.

What happens to the information?

All the information you provide in this study is completely confidential and will remain anonymous. No individual will be identifiable. We will follow ethical and legal practice and the information you give will be held in the strictest of confidence. Relevant sections of your medical records may be looked at by the researchers or members of your NHS clinical team, where it is relevant to your participation in this study.

All personal information will be stored in a locked cabinet or in a password protected computer file on a password protected computer in a locked office at the NHS Hospital site for four years. It will then be destroyed. No personal details will leave the hospital at any time. The data from the study will be analysed and may be published in an academic journal, but no identifiable information will be included. You can request that your data is destroyed by contacting the researcher.

What if I change my mind during the study?

You are under no obligation to take part in this study. Taking part will not affect any aspect of your care from your hospital or any other NHS services. If you wish to withdraw from the study at any stage, please contact the researcher, Ania Grodzziej, using the contact details at the end of this sheet. You will then be immediately withdrawn from the study. If you have already completed the questionnaires, then your data will be destroyed.

Are there any risks?

We don't envisage any negative consequences for you in taking part in this study. However, it is possible that completing questionnaires about your experiences may raise some emotional or distressing feelings. You have the opportunity to complete the questionnaires alone, or with the support of a friend, family member, or member of your healthcare team. You can also contact a member of the research team if you need support to complete the questionnaires, or if you have any other queries.

If you feel upset or distressed when completing the questionnaires, or have any other questions or concerns, then please don't hesitate to make use of the following sources of support to talk things through (contact details at the end of this information sheet):

- Contact the primary researcher, Ania Grodzziej (Clinical Psychologist in training).
- Contact the research supervisor, Dr Andrew Medley (Clinical Psychologist – University of Bath & RUH Bath Oncology Centre).
- Contact your Clinical Nurse Specialist or another member of your healthcare team.

Any of the above people will be able to talk through your concerns with you and discuss options for further support, commensurate with your wishes.

Who has approved this study?

An independent ethics committee reviews all research in the NHS in order to protect your safety, rights, wellbeing, and dignity. Approval for this study was given by the Department of Psychology's Ethics Committee at the University of Bath, and an NHS West of Scotland Research Ethics Committee 3.

How will the findings be used?

The findings of this study will help to guide and inform psychological support services in this region and beyond, especially in relation to better managing fear and anxiety after treatment. The results of this study will also contribute to the researcher's thesis for a Doctorate in Clinical Psychology from the University of Bath. Finally, the researcher hopes to submit the study to academic journals for publication and it may be presented at conferences. A summary report will be sent to all NHS oncology sites involved in this project.

What if I have more questions or do not understand something?

Please feel free to ask any questions by contacting the researcher, Ania Grodzziej, on the contact details at the end of this sheet. If there are any issues that cannot be resolved with the researcher, please contact the supervisor for this research, Dr Andrew Medley, on the details at the end of this sheet. If you have any other general questions about taking part in a research study or if you require further advice or support, you can contact a member of the patient advice and information service (PALS):

Royal United Hospital, PALS Bath

Address: RUH Bath NHS Trust, Combe Park, Bath, BA1 3NG
Tel: 01225 825656

Southmead Hospital, PALS Bristol

Address: South Plaza, Marlborough Street, Bristol, BS1 3NX
Tel: 0117 900 3433

Great Western Hospital, PALS Swindon

Contact Telephone Number: 01793 604031
Address: Marlborough Road, Swindon, Wiltshire, SN3 6BB

What happens next?

Please think about whether or not would you like to take part in this research. Discuss it with others if you wish and contact us on the below contact details with any questions you may have. If you wish to participate please read and fill in the consent form and included questionnaires. You can return them to us in a pre-paid envelope, or you can leave them for us to collect from your oncology clinician in your hospital. Thank you.

Contact details:

Researcher: Ania Grodzziej

Clinical Psychologist in Training, Department of Psychology, University of Bath.
Telephone: 01225 385745. Email: a.e.grozdziej@bath.ac.uk

Supervisor: Dr Andrew Medley

Research Tutor and Clinical Psychologist, University of Bath & RUH Bath Oncology Centre.
Telephone: 01225 383788.

Appendix C4. Information relevant to ethical review

WoSRES

West of Scotland Research Ethics Service



West of Scotland REC 3

Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 04 July 2014

Direct line 0141 211 2482
Fax 0141 211 1847
E-mail WoSREC3@ggc.scot.nhs.uk

Ms Ania Grodziej
Clinical Psychologist in Training
Taunton and Somerset NHS Foundation Trust
Department of Psychology
University of Bath, 6 West 0.9
Claverton Down, Bath
BA2 7AY

Dear Ms Grodziej

Study title: Fear of cancer recurrence and health behaviours in breast cancer survivors: the role of health anxiety and mental defeat.
REC reference: 14/WS/1018
IRAS project ID: 155461

Thank you for your letter of 2nd July 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Mrs Liz Jamieson, wosrec3@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

| <i>Document</i> | <i>Version</i> | <i>Date</i> | |
|---|----------------|--------------|--|
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University indemnity] | 1 | 30 May 2014 | |
| GP/consultant information sheets or letters | 2 | 26 June 2014 | |
| IRAS Checklist XML [Checklist_04062014] | | 04 June 2014 | |
| Letter from sponsor [Letter from sponsor] | 1 | 27 May 2014 | |
| Letter from statistician [Academic approval letter] | 1 | 30 May 2014 | |
| Other [CV Professor Salkovskis] | 1 | 30 May 2014 | |
| Other [Reminder Letter] | 1 | 26 June 2014 | |
| Other [University indemnity 2] | 1 | 30 May 2014 | |
| Participant consent form | 2 | 26 June 2014 | |
| Participant information sheet (PIS) | 3 | 26 June 2014 | |
| Participant information sheet (PIS) [Staff Information Sheet] | 2 | 30 May 2014 | |
| REC Application Form [REC_Form_04062014] | | 04 June 2014 | |
| Research protocol or project proposal | 2 | 26 June 2014 | |
| Response to Request for Further Information [Letter] | | 02 July 2014 | |
| Summary CV for Chief Investigator (CI) [Brief CV Ania Grodziej] | 1 | 30 May 2014 | |
| Summary CV for supervisor (student research) [CV Dr Medley] | 1 | 30 May 2014 | |
| Validated questionnaire [Questionnaire Pack] | 3 | 30 May 2014 | |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

| |
|-------------------|
| 14/WS/1018 |
|-------------------|

| |
|---|
| Please quote this number on all correspondence |
|---|

With the Committee's best wishes for the success of this project.

Yours sincerely



On behalf of
Mrs Rosie Rutherford
Alternate Vice Chair

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Professor Jane Millar*
Dr Alia Ataya, Research & Innovation, Southmead Hospital

WoSRES
West of Scotland Research Ethics Service



Ms Ania Grodzziej
Clinical Psychologist in Training
Taunton and Somerset NHS Foundation Trust
Department of Psychology
University of Bath, 6 West 0.9
Claverton Down, Bath
BA2 7AY

West of Scotland REC 3
Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 24 September 2014
Direct line 0141 211 6270
E-mail WoSREC3@ggc.scot.nhs.uk

Dear Ms Grodzziej

Study title: Fear of cancer recurrence and health behaviours in breast cancer survivors: the role of health anxiety and mental defeat.
REC reference: 14/WS/1018
Amendment number: REC Ref AM01
Amendment date: 23 September 2014
IRAS project ID: 155461

Thank you for your letter of 23 September 2014, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

| Document | Version | Date |
|---|--------------|-------------------|
| Notice of Minor Amendment | REC Ref AM01 | 23 September 2014 |
| Other [Macmillan Voices website - Research Advertisement] | 1 | 12 September 2014 |
| Other [Questionnaire: Relating to Self Care] | | |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

| | |
|--------------------|---|
| 14/WS/1018: | Please quote this number on all correspondence |
|--------------------|---|

Yours sincerely

Abibat Adewumi

Ms Abibat Adewumi
Assistant Coordinator

Copy to: *Dr Alia Ataya, Research & Innovation, Southmead Hospital*
Professor Jane Millar

WoSRES
West of Scotland Research Ethics Service



Ms Ania Grodziej
Clinical Psychologist in Training
Taunton and Somerset NHS Foundation Trust
Department of Psychology
University of Bath, 6 West 0.9
Claverton Down, Bath
BA2 7AY

West of Scotland REC 3

Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 06 February 2015

Direct line 0141 211 2482
Fax 0141 211 1847
E-mail WoSREC3@ggc.scot.nhs.uk

Dear Ms Grodziej

Study title: Fear of cancer recurrence and health behaviours in breast cancer survivors: the role of health anxiety and mental defeat.
REC reference: 14/WS/1018
Amendment number: REC Ref AM02 Minor
Amendment date: 05 February 2015
IRAS project ID: 155461

Summary of Minor Amendment: Sending on a very brief standard demographic information form to participants who have consented to take part in the study.

Thank you for your letter of 05 February 2015, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

| Document | Version | Date |
|---|--------------------|------------------|
| Notice of Minor Amendment [Medley Full Approval Letter] | REC Ref AM02 Minor | 05 February 2015 |
| Other [Demographic Form (e-mail version)] | 1 | February 2015 |
| Other [Demographic Form (postal version)] | 1 | February 2015 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

14/WS/1018:

Please quote this number on all correspondence

Yours sincerely



Mrs Rose Gallacher
Assistant Co-ordinator

Copy to:

Dr Alia Ataya, Research & Innovation, Southmead Hospital
Professor Jane Millar
Dr Andrew Medley



Professor Jane Millar OBE
Pro-Vice-Chancellor Research

Vice-Chancellor's Office
Bath BA2 7AY
Tel: 01225 386141
Email: Pro-vc-research@bath.ac.uk

Miss Ania Grozdziej
Department of Psychology

27 May 2014

Dear Ania

Fear of Cancer Recurrence and Health Behaviours in Breast Cancer Survivors: The Role of Health Anxiety and Mental Defeat


I am pleased to confirm that the University is prepared to act as sponsor under the Department of Health's Research Governance for Health and Social Care (2005) subject to the following:

1. The University requires you, as Chief Investigator, to conduct the study in compliance with the requirements of the Framework so it is able to meet its obligations as sponsor.
2. University professional indemnity and insurance will apply to the study as appropriate, within the UK.
3. As the Chief Investigator for the study, the University requires you to comply with the University policy on research data and all systems of good practice.
4. Substantial amendments and reports should be submitted to the undersigned.

Yours sincerely

A handwritten signature in black ink, appearing to read "Jane Millar".

Professor Jane Millar
Pro-Vice-Chancellor

| | |
|--|---|
| <p>Dr Andrew Medley Research Tutor & Clinical Psychologist Member of Psychology Ethics Committee Telephone +44 01225 383788 E-mail: A.R.Medley@bath.ac.uk</p> | <p> UNIVERSITY OF BATH Department of Psychology Bath BA2 7AY · United Kingdom</p> |
|--|---|

10th July 2014

Dear Ania

Ethics application: 14-174

Title of project: Fear of cancer recurrence in breast cancer survivors

The Psychology Ethics Committee have considered your ethics proposal for the above study and have given it full ethical approval.

Best wishes with your research.

Dr Andrew Medley
Research Tutor & Clinical Psychologist
Psychology Ethics Committee

Dear Andrew,

Thank you for your request, and for providing the attachment. These amendments seem entirely reasonable, so please accept this email as confirmation of approval by Chair's action.

Good luck with the project.

Best wishes
Michael

--

Michael J. Proulx, PhD

Senior Lecturer [Associate Professor] in Psychology
Department of Psychology
University of Bath
m.j.proulx@bath.ac.uk
<http://people.bath.ac.uk/mjp51>

Quoting Andrew Medley <A.R.Medley@bath.ac.uk>:

Dear Chair

I write to outline two minor changes that we would like to make to a clinical psychology doctorate study that has received full NHS ethics approval and approval through our local R&D committee on 10th July 2014 (14/174 - Fear of cancer recurrence in breast cancer survivors). I have contacted the NHS ethics committee who approved the study (via proportionate review on 4th July: West of Scotland REC 3; IRAS project ID: 155461), who advised that I refer the changes for local R&D approval.

This is a questionnaire-based study exploring health anxiety and fear of recurrence in people who have completed treatment with curative intent. The two proposed changes are outlined below:

1. Very recent research evidence (since we designed our original protocol) has identified self-compassion as a potentially important mediator of distress in cancer patients. Accordingly, we're very keen to include a short 12-item self-report measure of self-compassion, which is very widely used and has excellent psychometric properties (attached). The scale presents statements relating to self-care and compassion at times of stress, with Likert-scale responses. It is markedly less likely than other questionnaires in our pack to prompt adverse emotional reactions, so does not, in my view, present any ethical concerns.
2. We would like to add an additional non-NHS source for participants, which is the Macmillan Voices website (national cancer charity). We propose to post an advertisement inviting people to contact us if they are interested in taking part in the study. Participants

would then receive the same information and go through the same consent procedure as approved in our protocol.

I'd be hugely grateful if you could consider the above changes through Chair's action. The project forms part of the trainee's (Ania Grozdziej) doctoral portfolio, so deadlines are naturally tight.

We look forward to hearing from you.

With my best wishes
Andrew

--

University of Bath <<http://www.bath.ac.uk>>

Dr Andrew Medley, Research Tutor & Clinical Psychologist *University of Bath

<<http://www.bath.ac.uk>>*

Clinical Psychology Doctorate Programme, 6 West 1.27, Claverton Down Campus, Bath
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A.R.Medley@bath.ac.uk